

Confidentiality and Respect

Impact of Attitudes and Conduct of Healthcare Professionals towards Home Educating Families

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Abstract

This research demonstrates that some home educators may already experience discriminatory attitudes or inappropriate breaches of confidentiality. Data breaches of non-clinical data alone were repeatedly demonstrated to have significant impact on trust and practitioner-patient relationships. Such experiences can cause some to feel unsafe accessing health care. Whilst this is a significant problem, it is one that could be readily addressed by improved education and communication.

This study also provides evidence that any future introduction of mandatory non-consensual data-sharing requirements would significantly impact patients' sense of safety in accessing health care and damage the vital trust-based practitioner-patient relationship that is founded on confidentiality and consent, thus creating obstacles to accessing healthcare for families.

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1 Summary

- This research demonstrates that some home educators already may experience discriminatory attitudes or inappropriate breaches of confidentiality. Data-breaches of non-clinical data alone were repeatedly demonstrated to have significant impact on trust and practitioner-patient relationships. Such experiences can cause some to feel unsafe accessing health care. Whilst this is a significant problem, it is one that could be readily addressed by improved education and communication.
- This study also provides evidence that any future introduction of mandatory non-consensual data-sharing requirements would significantly impact patient's sense of safety in accessing health care and damage the vital trust-based practitioner patient relationship that is founded on confidentiality and consent, thus creating obstacles to accessing healthcare for families.
- This research indicates that there would be resulting damage to the well-being of children for whom there were no grounds for concern, with no compensating benefit for children at risk since health care professionals are already enabled to share information on individual cases if there is reason to believe a particular child is at risk of significant harm. Therefore, the study concludes, it is not reasonable or proportionate to mandate routine and non-consensual collection of data from health care sources on all children, just in case this might identify any educational issues in a hypothetical few. The study further demonstrates that propagating discriminatory attitudes of suspicion and negative stereotypes, promoting false connotations and breaching confidentiality, would risk cultivating a climate of mistrust that further damages the trust-based clinician patient relationship.
- The study notes the present Welsh Government's proposals to establish extensive databases containing not only identifying details of children but contact details (collected without consent or even knowledge) of all persons with parental responsibility, or any form of care role, or any educational influence or input into a child's life, as well as on additional learning needs and provisions required for these. Local authorities (LAs) would have legal position to use GP services as data providers. Furthermore, whilst medical records would at present be outside the remit of the suggested changes, enacting the database section of the Children's Act 2004 would permit the range of data required to be provided by health care sources to be very widely extended to include whatever details any future or current government ministers may choose to specify.
- The study concludes that such proposals are clearly controversial. The use of health care services as data sources is unethical, counterproductive to any aim of promoting the well-being of children and sets dangerous precedents. Apart from the potential range of data that LAs are encouraged to seek out, access to health care alone is a matter of confidentiality and is not something to which barriers should be created. The GMC are clear that there is no difference between clinical and non-clinical data when it comes to confidentiality.
- Furthermore, the creation of obstacles to accessing health care for families by any such proposals raises the potential of then being used to justify any subsequent instigation of

local authority monitoring of families' access of health care, for example frequency of visits. The inbuilt capacity for increased data sharing and the precedent such proposals would set for health care providers to be sources and holders of data for local authorities create such a potential. It would clearly be unethical to knowingly create problems in order to justify increased surveillance of behaviour, especially problems that impact health care of families.

- The study highlights clear ethical and legal precedents which support such objections to routine non-consensual, confidentiality-breaching data sharing, including:
 - The GMC's own objections to such proposals by the Welsh Government in 2020 in addition to their well-established guidance on confidentiality.
 - The UK government's necessary U-turn on data sharing from health care sources on asylum seekers in 2018,
 - Professional bodies guidance on confidentiality such as the RCOG's 2024 guidance, developed in collaboration with various healthcare bodies to protect confidentiality of women suspected of procuring illegal abortions.
 - The Supreme Court's finding against the Named Person's Bill on grounds of protecting privacy and family life.
 - The abandonment of the "Contactpoint" database of children, having been heavily criticised by a wide range of groups including the BMA for privacy, security and child protection reasons and because of risks of breaches of patient confidentiality. This had been based on the English equivalent within the Children's Act 2004 of the s29 being used to justify the present Welsh government proposals.

- The study concludes it is vital that health care providers, the departments and trusts that employ them, and professional bodies that represent them ensure that health care sources are not mandated to routinely share data about patients with local authorities.

2 Research

2.1 Introduction and context:

Two fundamental pillars of healthcare, that protect both patients and staff, are **confidentiality** and **informed consent**.

Confidentiality is the ethical and legal duty of health care workers to protect the privacy of their patients and clients, built upon the foundation of a confidential, trust-based relationship between patients and those who provide health care services.

Clinicians will be aware that **informed consent** has to not only include the risks, benefit, likely outcomes and alternatives to a proposed action or intervention, but also the right to refuse it. Consent is not a once-and-for-all concept, consent must be voluntary, and practitioners have a legal and ethical duty to ensure it is informed.

Whilst no-one would dispute that information can be shared if there are legitimate reasons to suspect in an individual case that a child may be “at risk of significant harm”, there have been occasions where confidentiality has been breached and the principles of informed consent ignored when home educating families have accessed health care, purely because they home educate.

Home education is not just a lawful option, it is the default option. Home education is where parents continue their legal responsibility for ensuring their children receive a suitable education rather than delegating this task to a school.

Legally, education is the responsibility of parents, not authorities, wherever that education is delivered or whoever delivers it. Parents may of course choose to delegate the task by choosing to enrol their child in a school, but parents are still ultimately responsible as is stated in section 7 of the Education Act 1996. This becomes apparent when one considers parents are unable to sue a school or local authority should either of these services fail to provide a suitable education for the child, as the duty remains with the parent.

Home education is not a safeguarding risk, as the Department for Education acknowledges (https://assets.publishing.service.gov.uk/media/5ca21e0b40f0b625e97ffe06/Elective_home_education_guidance_for_LAv2.0.pdf, p. section 7.3).

Indeed, research has shown that home educated children are at lower risk of abuse or neglect within the home, despite a tendency of authorities to treat them with increased suspicion (<https://www.educationotherwise.org/home-education-and-the-safeguarding-myth-analysing-the-facts-behind-the-rhetoric/>)

Home education is not the same as ‘homeschooling’, though the terms are often conflated. ‘Homeschooling’ more readily applies, for example, to ‘lockdown learning’ during pandemic school closures, or practice in other countries. One of the many advantages of home education is the capacity to utilise a wide range of learning approaches and/or child-led, child-focused pedagogies, many of which may not replicate a school-at-home style.

2.1.1 Aims of this research:

This research seeks to objectively document the opinions and experiences of home educators in relation to accessing health care, addressing any breaches of confidentiality or informed consent or experiences of discriminatory or stigmatising behaviour from health care sources, including examples of lived experience of the impact of these issues.

This study particularly seeks to identify the experiences and potential impact of non-consensual data sharing by health care services with local authorities.

2.1.2 Intended use of this research:

(1) It is hoped that this research will be useful for health care professionals (HCPs), for the professional bodies that represent them, and for departments, surgeries and hospitals that may employ them, to aid development of practices and policies that are informed, respectful and that remove any such hindrances to healthy communications and relationships with home educating families.

(2) However, as well as the long term need to address the experience of healthcare for home educators, there is a further urgent reason to engage with health care professionals and the bodies that represent or employ them on the potential damage of breaching confidentiality and sharing data without consent.

There are considerations and proposals that health care services should be required by law to share identifying data on ALL children with local authorities without parental consent so that local authorities can then make formal enquiries about the educational provision for all children who are not on a school roll.

This is undergoing consultation in Wales at present, over intentions to mandate Local Health Boards (LHBs) and GP services to be considered as data-holders for the local authority and to share the data of all children without consent. A trial roll out is planned in several counties in Wales imminently.

There is no indication of additional funding to cover time and costs involved for health care providers such as GP service contractors.

The proposals are not to address issues with school attendance, as they assume that education is automatically suitable for any child on the school roll, even if their attendance is 0%.

Rather, they would involve mandating disclosure from GP service contractors and LHBs the identifying data on some half a million children in Wales (all children of “compulsory school age”). 98% of the contact information gathered from GPs/LHBs would then not be used for those particular databases, but with the potential of being used for other purposes, as will be discussed.

It is vital that professional bodies representing health care professionals, and clinicians themselves, are fully aware of the likely impact of non-consensual and mandatory data sharing, to enable them to make appropriate representations for their members and for the patients they care for in their responses to the present consultation (closing date 25th April 2024). (<https://www.gov.wales/children-missing-education-database>)

For the purposes of this survey:

- “Health care services” is used to include health care professionals, health care sources or departments, NHS trusts, and - in Wales - local health boards.
- “Health care professionals” (HCPs) is used to denote not only clinicians with direct contact with patients but also any support staff that are part of the process of patients accessing health care.

2.2 Methods:

This research is drawn from an online survey conducted by HEACH (Home Educators Advocating for Confidential Healthcare) - an affiliation of clinicians and home educators in the UK concerned with preserving confidential access to health care.

The survey was conducted via a Google Forms survey comprising multiple choice, closed and open response questions to determine the opinions and experiences of respondents. The survey questions are listed in Appendix A.

The survey ran between 25th February and 12th March, 2024, and was publicised through a number of home educator support groups, with requests to share to any relevant participants.

Respondents were self-selected and no attempt was made to identify or normalise for population characteristics other than identifying which UK nation the respondent lived in or where any incidents occurred, and whether or not participants were home educating parents or young people.

In particular, no attempt was made to select only respondents who had previously had negative experiences of access to healthcare, thereby enabling a combined study of past experiences with a survey of present opinions of home educators regardless of past experiences.

Participants were assured of anonymity, were not required to identify themselves and were requested not to share information that would identify their families.

All questions were optional, and any identifying features in comments have been redacted in this report.

Other than the initial explanation of the purpose of the survey (see Annex A), there was no preceding discussion in the text on potential merits or concerns in relation to the issues addressed, in order to gather experiences and opinions as objectively as possible.

Each respondent was asked to give explicit consent to their responses being used in anonymised collation and analysis. Any responses without such consent were deleted and not included in the analysis.

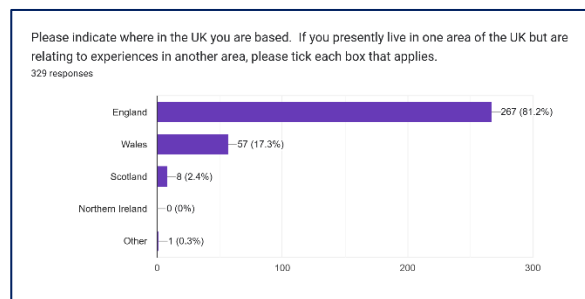
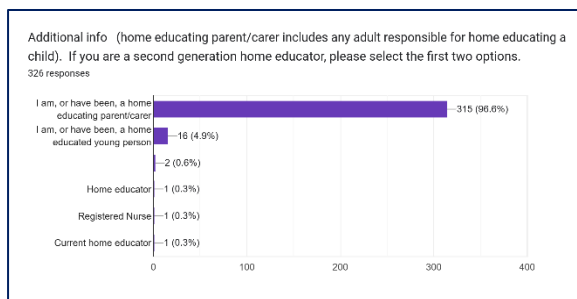
2.3 Results:

2.3.1 Demographics of respondents.

There were 335 completed responses received within the timeframe, 5 of which were not included in this analysis as explicit consent had not been demonstrated. Hence 330 responses were analysed.

96.6% of respondents were present or former home educating parents or carers, 4.9% were present or former home educating young people, with 10 of these respondents being second generation home educators, i.e. now home educating their own families having been home educated themselves.

81.2% of respondents were from England, 17.3% (57 respondents) from Wales.



Figs. 1a and 1b – Demographics of respondents.

1. Initial opinions expressed:

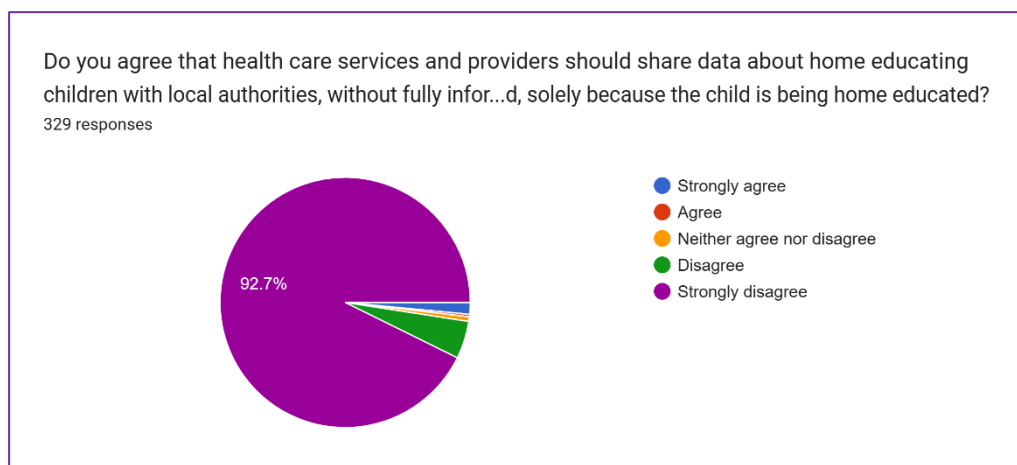


Fig. 2.

- a. **97.6% of respondents disagreed** with the concept of health care services and providers sharing data about home educating children with local authorities, without fully informed explicit consent of parent or child, solely because the child is being home educated, with **92.7% strongly disagreeing**.

If only the respondents from Wales are considered (where, as discussed, there are proposals to mandate routine, confidentiality breaching, non-consensual data-sharing by local health boards and GP service providers to local authorities to facilitate inspection of home education provision), 100% of respondents disagreed with the concept of health care services and providers sharing data about home educating children with local authorities, without fully informed explicit consent of parent or child, 89% strongly disagreeing. Thus, no respondents from Wales agreed with such a concept or held a neutral opinion.

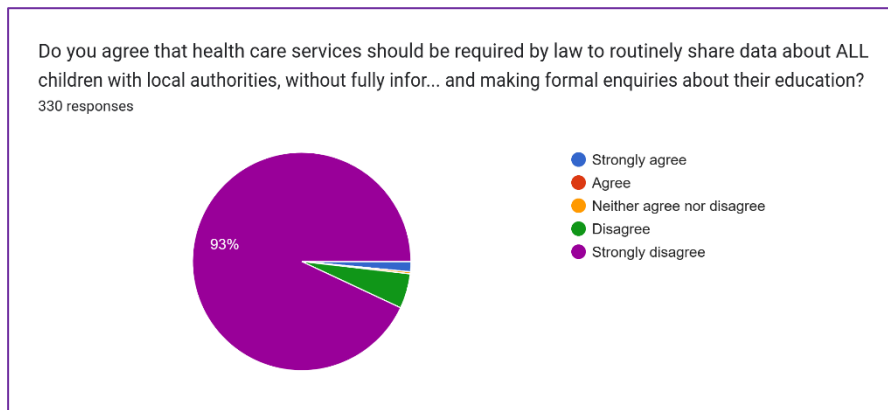


Fig. 2b.

- b. 98.2% of respondents disagreed with the concept of health care services being required by law to routinely share data about ALL children with local authorities, without fully informed and explicit consent of the child or parent, for the purposes of the LA developing a list/database of children not on the school roll and making formal enquiries about their education, with 93 % of respondents strongly disagreeing.

Separate analysis of responses from Wales demonstrated that no respondents from Wales agreed with the concept of non-consensual data-sharing with local authorities. This is of particular note given the Welsh Government's proposals for such measures.

2.3.2 In terms of previous experiences:

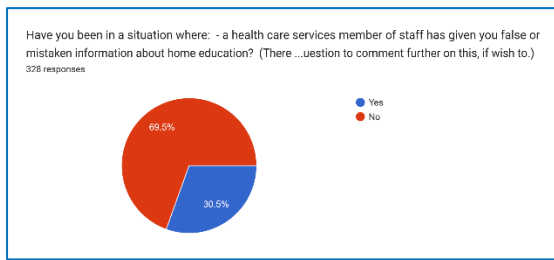


Fig. 3a.

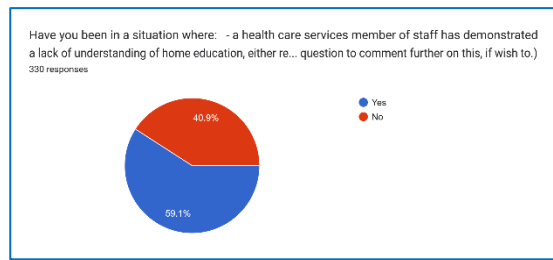


Fig. 3b.

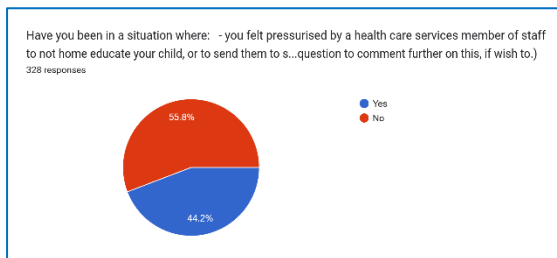


Fig. 3c.

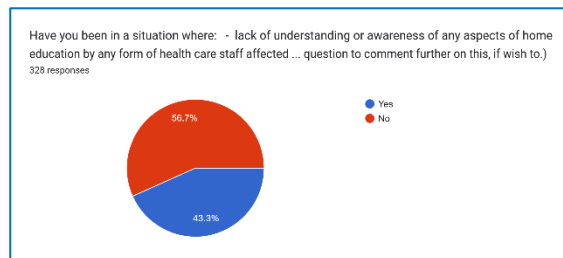


Fig. 3d.

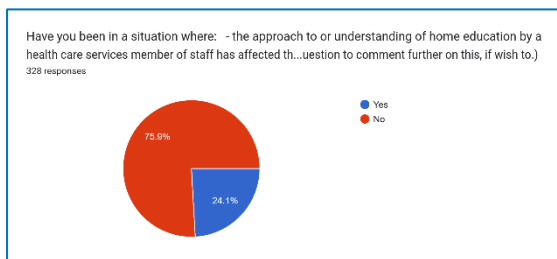


Fig. 3e.

- a. 30 % of respondents reported they had been in a situation where health care services member of staff had given them **false or mistaken information** about home education.
- b. 59.1% reported having experienced a health care services member of staff had demonstrated a **lack of understanding** of home education, either regarding the legalities or the day-to-day practicalities and approaches.
- c. 44.2% reported having felt **pressurised** by a health care services member of staff to not home educate their child/ to send them to school instead, or having felt that the health care professional considered home education to be a **less valid approach** to education than school based education.
- d. 43.3% reported that a lack of understanding or awareness of any aspects of home education by a member or members of health care staff had affected their family's **relationship with clinicians or health care services**.
- e. 24.1%, almost a quarter of respondents, reported that the approach to or understanding of home education by a health care services member of staff has affected the **clinical care** their family were able to access.

- f. The experiences demonstrated in Figs. 3a to 3e were cited with reference to a range of types of health care professionals:

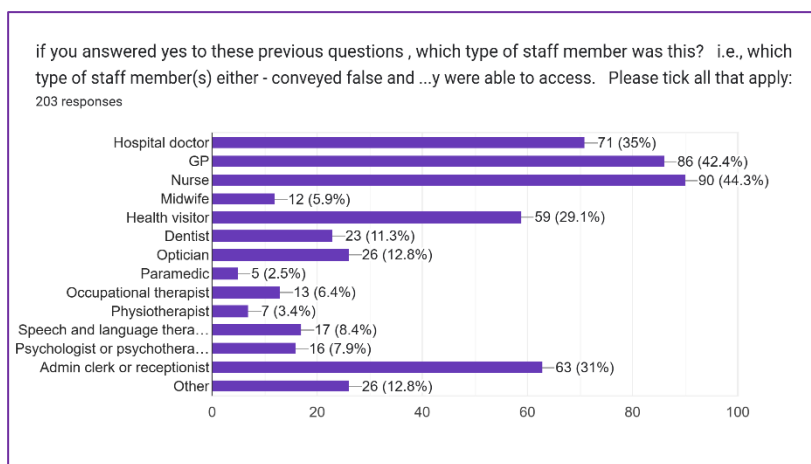


Fig. 3f.

- g. Accounts of previous experiences with health care professionals:

A representative collation from the many free text responses illustrating the main trends, issues and experiences noted can be found in Section B. Reading these is vital, not only to verify the summary below, but also to enable the reader to appreciate the perspectives and experiences of so many home educators, to enable reflection on personal practice and to understand the powerful nature of the impact of such experiences on access to health care.

- Not all encounters home educators have with HCPs are bad, of course - but what makes the difference?
- Examples of HCPs not understanding legalities of EHE.
- Examples of inappropriate data-sharing without consent from health care sources purely because home educated.
- Examples of HCPs not understanding how home education works and functions.
- Examples of institutionalised discrimination (including false conflation with safeguarding).
- Examples of difficulties for home educators accessing health care due to negative, ill-informed or discriminatory attitudes within health care provision.
- Examples of lack of understanding of HCPs in relation to school trauma.
- Examples of HCPs expressing negative personal opinions about EHE to parents.
- Examples of home educated children being directly exposed to expressions of negative personal opinions or discriminatory attitudes
- Examples of damage to practitioner patient relationships.

2.3.3 Previous experiences of non-consensual data sharing.

- a. 32.7 % of respondents indicated that they believed their family’s data had been shared without their consent, with 11.1% of these stating they had evidence to verify that belief (Fig. 4a).

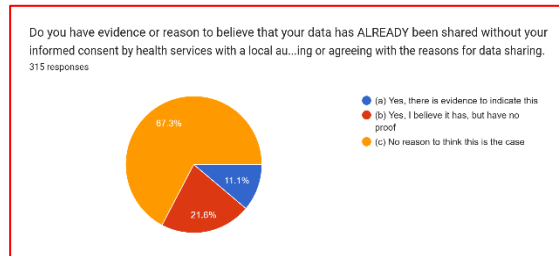


Fig. 4a.

- b. Respondents indicated that they believed a range of types of health care professionals had breached confidentiality in this way, as demonstrated in Fig. 4b.

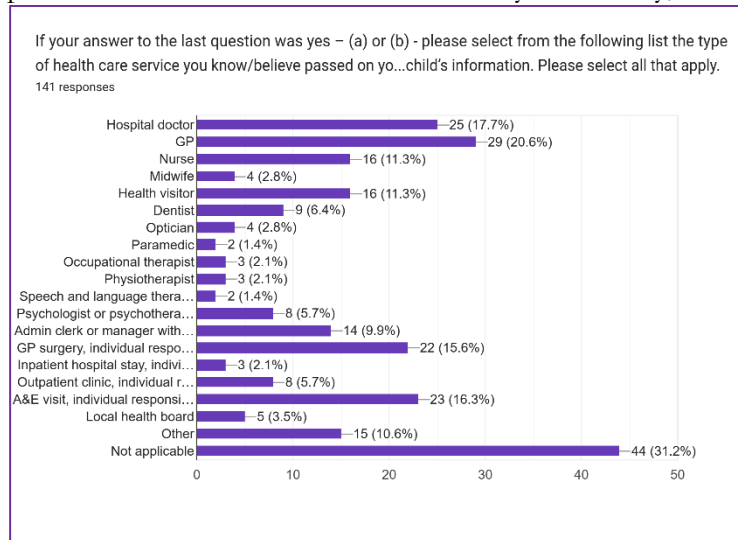


Fig. 4b.

- c. 104 respondents who believed or knew that their data had been shared without consent by a health care services member of staff indicated the effect this had on their families. 71 of these 104 respondents (**68.2%**) indicated some negative effect, with 30 of these (28.8%) stating the effect had been a strongly negative one. Whilst 33 of the 104 respondents (31.7%) indicated that there had been neither a positive nor negative effect, no respondents indicated that known or perceived non-consensual data sharing and breaches of confidentiality had had any form of positive impact or outcome for their family.

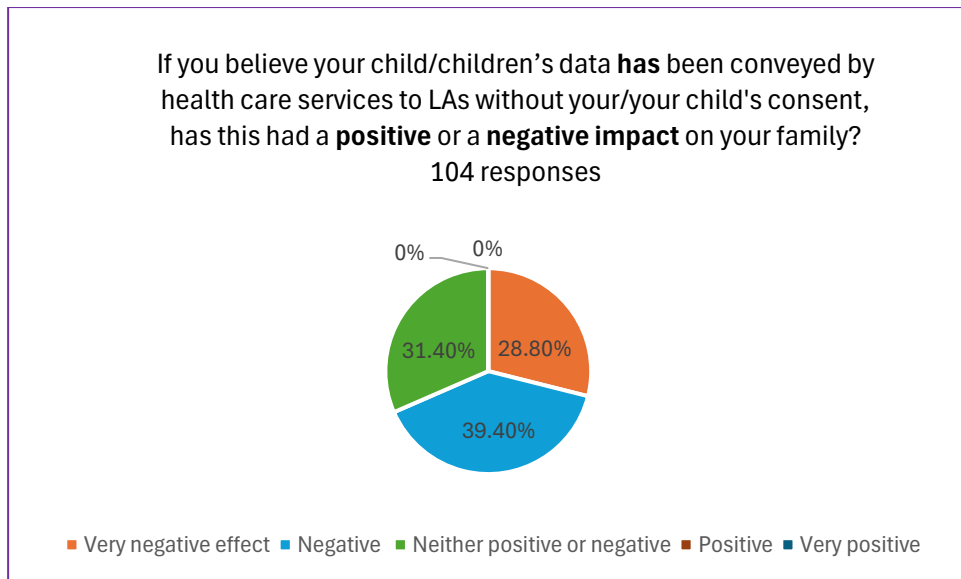


Fig. 4c.

- d. A key consequence of such incidents could be the potential impact on other families' approaches to health care when such accounts are known within the community. Therefore, respondents were asked how the **potential** of their family's data being shared without their consent with local authorities by health care services would impact their trust in clinical care providers. 96.9% of respondents reported that the potential of this happening weakened their trust in health care services, 87.2% strongly so.

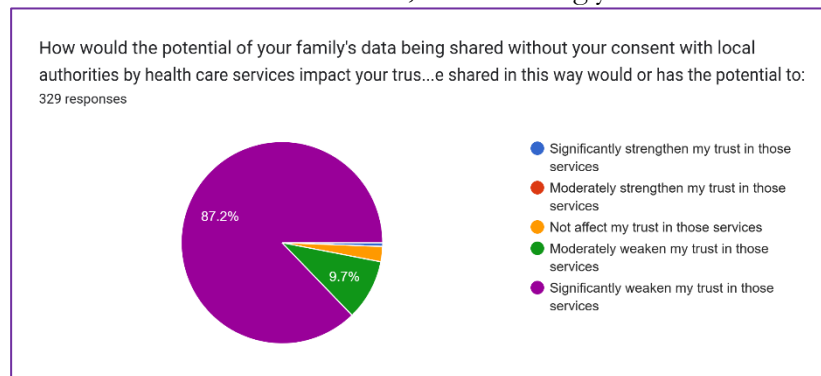


Fig. 4d.

- e. **95.2%** of respondents indicated they believed that placing a **legal duty** on health care services to routinely share children's data with local authorities (without consent) would be likely to have a **negative effect** on access to routine health care provision for home educating families, with 81.5% stating that they believed this would be a **strongly negative effect**.

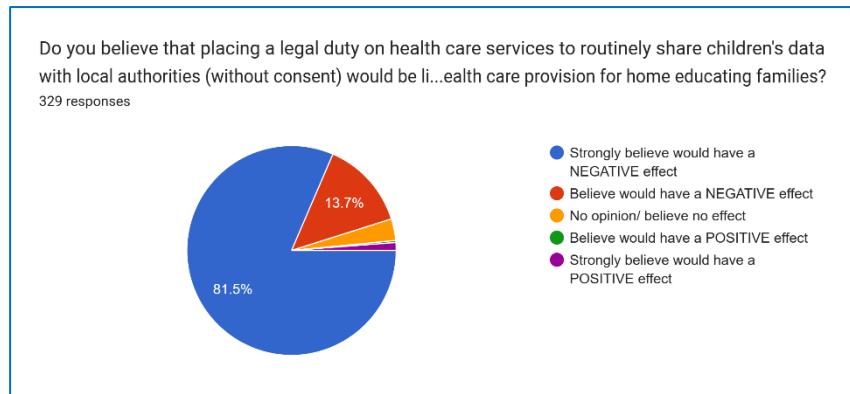


Fig. 4e.

2.3.4 Experience of the complaints process:

- f. 29 respondents (9%) stated that they had had grounds to make a complaint or raise concerns about some form of health care service or staff member because of issues relating to home education and had taken the step to make that complaint.

A further 68 respondents (21.2%) stated that they had had such grounds to make a complaint or raise concerns about some form of health care service or staff member because of issues relating to home education but had not proceeded to make a complaint or raise concerns.

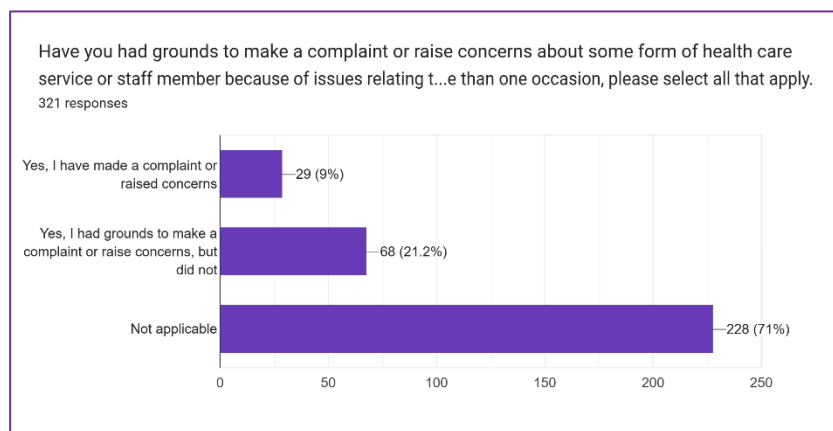


Fig. 5a.

- g. Of the 36 respondents that had made a complaint or raised concerns and indicated the extent of the effect of the outcome,
- i. 3 (8%) stated that there had been a significant improvement as a result,
 - ii. 5 (13.9%) indicated there had been some improvement,
 - iii. 15 (41%) felt it had made no difference or that the complaint or concern had not been managed correctly,
 - iv. 11 (30%) felt that making a complaint or trying to raise concerns had made their situation more difficult or worse.

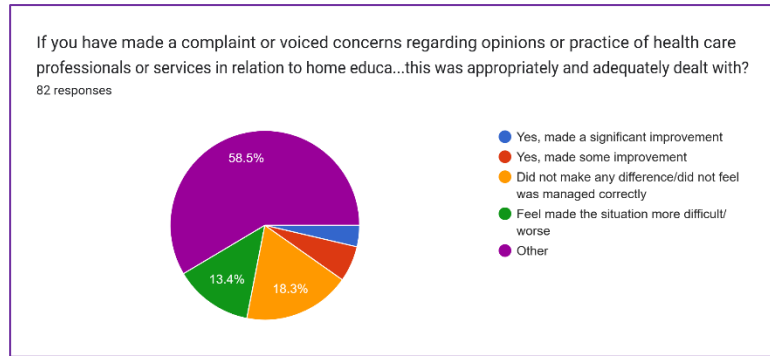


Fig. 5b.

Free text responses of experiences of making complaints did not demonstrate satisfactory outcomes, but rather dissatisfaction or hesitancy about the process. See Section B for a collation of relevant responses.

- h. Reasons given for not making a complaint or raising concerns with health care providers despite believing there were grounds to do so included:
 - i. Being concerned about potential or perceived negative effects of putting in a complaint or voicing concerns, or concerned in case doing so might make things "worse" (65%).
 - ii. Being unsure of how to make a complaint or voice concerns (25%).
 - iii. Not feeling it was worth the effort/feeling would not be listened to (47.5%).
 - iv. Being too busy to take the time/finding the process too time consuming (21.7%).
 - v. Finding the process too stressful (22.5%).

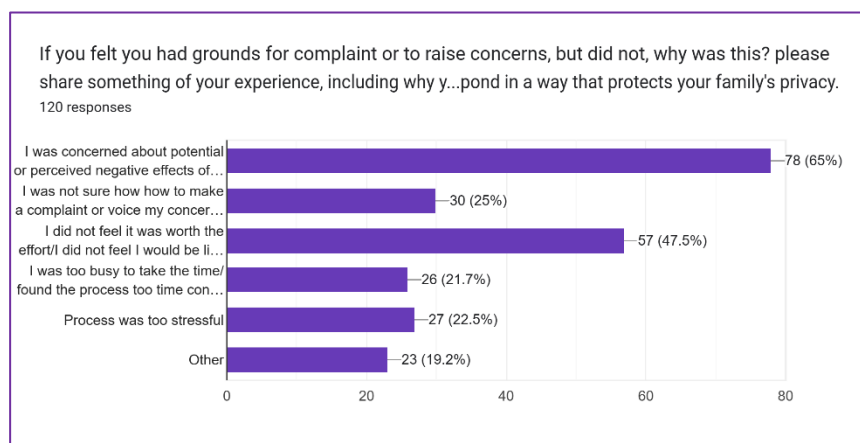


Fig. 5c.

- i. Free text responses for reasons for not making a complaint or raising concerns despite believing there were grounds to do so indicated the following reasons:
 - i. Fear.
 - ii. Doesn't/didn't make a difference.
 - iii. Was not/would not be heard, didn't believe would be listened to

- iv. Felt or had previously found that concerns would be dismissed, invalidated, or not understood.
 - v. Lack of regard for private life.
 - vi. Risk of subsequent malicious reporting.
 - vii. Worried about false accusations as a result of complaining.
 - viii. It would not change the outcome as damage already done.
 - ix. Temporary member of staff.
 - x. Felt would be gaslighted or turned upon.
 - xi. Reliance on the subject(s) of the complaint for necessary ongoing clinical care/Process would identify the complainant to the one complained about.
2. Families were given an opportunity to comment or add further information/views on the impact on home educating families of non-consensual data sharing of their data by health care services. A selected collation of free text responses is given in Section B.

Measures to mandate data-sharing between health care sources and LAs, and/or of individual experiences of negative attitudes of some HCPs in relation to EHE were stated by respondents to be likely to:

- a. Destroy all trust- people would not seek help from those whom they do not trust.
- b. Be self-defeating.
- c. Be destructive.
- d. Be dangerous.
- e. Leave law-abiding and loving families “vulnerable”.
- f. Could cause barriers to accessing services,
 - i. References included: may cause to second-guess/think twice about the need for the visit, could raise the bar for what needed to seek medical input, could cause reluctance to reach out to the health professionals if they felt that in some way it would cause significant harm or upset for the child and their family.
 - ii. Parents indicated that they do not want such barriers to be in place, demonstrating how they care about their families’ health and well-being, stating that they should not have to make a choice between health care and privacy/education.
- g. Give the impression that home educators cannot be trusted,
 - i. For example: would propagate damaging negative perceptions, legitimises and perpetuates the unfounded stereotype that home educated children are automatically at risk of harm, further embedding such ideas,
 - ii. Parents commented that data sharing without individual and specific indications assumes families are already likely to be guilty of something before any evidence has been presented.
 - iii. Comments also referred to how such mandates would create the assumption that something wrong must be going on in home educating families to justify the need to be checked up on.
 - iv. Would appear to provide evidence in people’s minds that the government are suspicious of home educators.
 - v. Implies that home education is a safeguarding issue when it is not.
- h. Damages relationships between home educators and HCPs as well as between home educators and local authorities.

- i. Be counter to the expressed belief that health care data should be completely confidential, that EHE children should have the same rights to confidentiality as anyone else.
- j. Be counter to the belief that home educated children should feel protected when seeking out healthcare.
- k. Reinforce negativity that could stop people accessing needed resources.
- l. Be a violation of confidentiality and of UN children's rights, including rights to privacy and family life.
- m. Blur roles, as health care should be just that – health care, with education not being the role of HCPs.
- n. Be discriminatory, as manner of education should not affect how treated by health services.
- o. Would cause a risk of data-leaks as LA data is not held under the same level of security as NHS data, which would be a safeguarding risk.
- p. Be a completely different issue to data sharing in individual cases where there are grounds to believe a child is at risk of significant harm (a measure that is already not just permissible, but a duty and which home educators indicated they endorsed), and therefore not be reasonable or proportionate.
- q. Place families under unwanted and unnecessary scrutiny and intrusion, placing them under microscopes.
- r. Deflect from giving time, money and attention to known cases where children genuinely need help and intervention, or from addressing failings of the school system.
- s. Not be consistent with precedents such as previous decisions not to share data from health care sources on asylum seekers, as this was found to be a deterrent to accessing health care.
- t. Perpetuate the damage of occasional errant and likely unlawful departmental policies to report children to authorities purely because they are home educated.
- u. Be sharing data with a local authority which parents may feel had already failed them, if children had been deregistered from school due to unmet needs or abuse/bullying.
- v. Cause a significant increase in stress for families, cause anxieties, create senses of insecurity or being demonised, feeling unsafe, unvalued or subpar to other families in ways that do not promote equality. The semantic field of responses also included words such as “fear”, “petrified”, “scared”.
- w. Risk worsening the already existing difficulties in accessing certain diagnostic and therapeutic aspects of health care.

2.3.4.1 Respondents were asked their opinions on what measures they believed would help prevent the kinds of situations referenced in this survey.

- x. Responses to a list of potential measures included:
 - i. Better education/advice about home education for health care staff from professional bodies that represent and advise them.
 - ii. Better education/advice about home education for health care staff from departments/surgeries/hospitals/trusts.
 - iii. Departmental/practice/hospital/trust policies that respect the privacy and autonomy of home educators and confirm that home education is not a safeguarding risk.

- iv. Better advice for health care staff and policy development within health care services that respect the privacy and autonomy of families in general.
- v. Government policies that respect the privacy and autonomy of home educators and do not treat home educators with suspicion.
- vi. Abandonment of government plans to mandate non-consensual sharing of data about children by local health boards and GP service contractors.
- vii. Home educators to be involved in construction of the education/advice/policies mentioned above to ensure they are appropriate, respectful and lawful.
- viii. Respectful and unbiased media representation of home education to better inform the community as a whole.

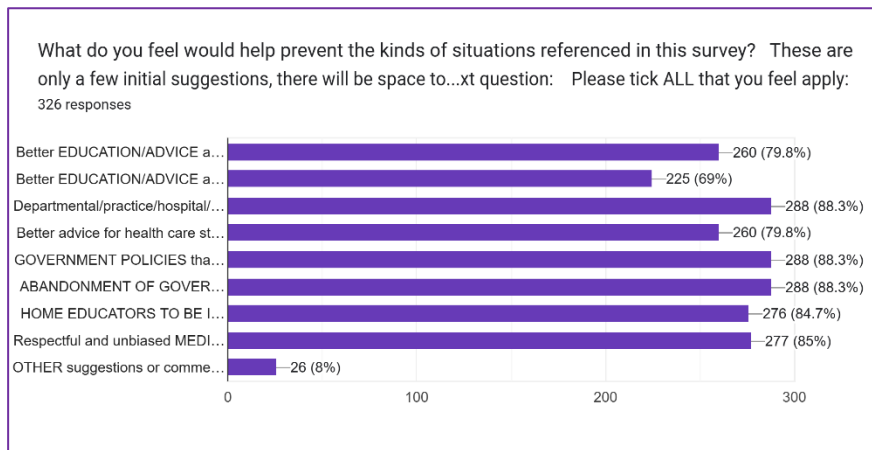


Fig. 7a.

Respondents were given an opportunity to expand on their choices or suggest other measures or opinions. Alongside the responses above, further suggestions included:

- The need for a consent form before data can be shared from NHS sources.
- The right to have data deleted from LA lists or databases if it had been provided without consent or unlawfully, that LAs should take no action to investigate the family and must write to the healthcare provider concerned if this has occurred.
- Adoption of consistent non-hostile approaches to home educators by LAs.
- The need to listen to families and to experienced home education advocates.

2.4 Discussion of results.

- This research has revealed the challenges faced by home educating families trying to protect their children from harm and ensure they have a globally healthy upbringing, free from trauma, discrimination whilst providing them with full access to health care and an optimal education. It demonstrates how discrimination, non-consensual data sharing and confidentiality breaches create barriers that, at best, are shown to risk inhibiting free and open communications and cause seeds of doubt to be sown that damage the vital trust-based practitioner-patient relationship. Such obstacles risk inhibiting access to health care for families who experience the consequences of such encounters and practices, or who are concerned about the potential risk of doing so.
- Whilst certainly not being the conduct of every HCP encountered and with contrasting reports of positive and encouraging engagement with supportive HCPs, one key barrier to accessing health care that this research identifies are discriminatory attitudes from some HCPs towards EHE families, some of which may have originated from or been endorsed by misleading training or departmental policies.
 - Such attitudes of individuals were seemingly often based on:
 - lack of knowledge of home education, including the legalities or how home education “works”,
 - confusion over the duties of individuals and
 - false conflation of home education with safeguarding issues.
 - However, responses indicated it was not necessarily lack of knowledge per se that resulted in problems, but rather unwillingness to abandon any misconceptions and to learn from patients’ experience.
- It would appear that there are some departmental policies or staff training processes that could be perpetuating such confusion and false conflation; however, it was beyond the scope of this study to investigate these.
- Respondents cited occasions when condemnatory or stigmatising statements, attitudes and approaches were conveyed by HCPs not only to parents and carers but also directly to home educated children.
 - The damaging effects of being victims of prejudice, whether inferred or expressed, whether in word or in action, are well recognised in society.
 - However, when children may already be dealing with mental health issues and/or recovering from the profoundly damaging consequences of school-trauma, discriminatory or condemnatory attitudes can be especially damaging.
 - The cultivation of self-worth is a vital aspect of child development, one that can be especially challenging when a child is learning to understand and develop appropriate strategies to deal with any additional learning needs they may have. At such developmental stages, especially if there are ALNs, exposure to such stigmatising or condemnatory experiences and attitudes can be particularly damaging.
 - There are potential indications of systemic failings in referral pathways. Investigation of these are beyond the scope of this study, although responses indicated that better education of clinicians would be likely to address many such issues, including for those who develop such pathways.
 - However, it does highlight the obstacles to accessing health care when education and health care become interchangeably entwined.

- There was no evidence of families wanting/preferring to avoid access to health care. Indeed, quite the opposite desire was evident. Parents were clearly seeking to safeguard their children from risk of harm, including harm from stigmatising and derogatory attitudes or communications, and demonstrating considerable determination to access optimal health care for their children despite such obstacles. The obstacles to accessing good health care in these instances are shown to lie with discriminatory attitudes and errant data sharing, not with the families. Parents reported not wanting to make complaints or report concerns despite being subject to discriminatory attitudes or having information about their families unlawfully shared, as they “desperately” wanted to access help from health care services and did not want to make access to health care more difficult.

- Whilst the survey did not ask specifically about what type of information had been shared, no parent specified that it was **clinical** information that had been inappropriately disclosed. Rather, responses indicated that it was primarily **non-clinical data regarding the identity of children and their mode of education** that had been shared without consent and **which had caused distress and breakdown in trust for many families affected.**

- One of the obstacles identified to open and confidential access to health care for home educating families were government and/or local policies that are perceived as perpetuating false connotations and/or treating home educators with suspicion.
 - This would include proposals to mandate nonconsensual data sharing on all children in Wales, to create a database containing extensive levels of information and the possibility of further increasing the amount of information required.
 - It is beyond the scope of this report to explore the full extent of impact on home educating families. More information can be provided by HEACH if required.
 - However, even if clinicians or others find it difficult to understand or do not agree with families’ concerns about proposals for such databases or why home educators prefer to keep LA involvement to a minimum, it remains the case that any differing viewpoints are not relevant. Confidentiality and the principles of good clinical care and trust-based practitioner-patient relationships mean that the **opinions and views of patients should be respected and honoured, even if they are different to those of the clinician.**
 - The fundamental point is that the families affected do not want these proposals to be enacted and have strongly indicated how these would have a detrimental impact on practitioner-patient relationships.

- Regarding the measures already in place to allow for confidentiality to be breached, and even occasionally informed consent to be bypassed, in those **individual cases** where there is **legitimate concern of risk of significant harm:**
 - No respondents disputed the use of such a vital safeguarding measure in individual cases if required, and many volunteered comments endorsing and agreeing with the existing provision in law to do so.
 - However, if families are deterred from being in a trusting relationship with their clinicians, then clinicians are less able to perform this vital and intrinsic role of spotting causes for concern in any individual cases, as well as noting when preventative measures could be of benefit. Therefore, clinicians should be free to use their professional judgement on whether confidentiality should ever be breached, and choice of approach to education should not be an influencing factor in this.

- Measures already exist to allow local authorities to fulfil their legal remit in relation to education. However, such measures are not the concern of health care providers and are not explored further here.
- It is not directly relevant whether or not a clinician, or a person representing them understands, or even agrees with, families who have concerns about other aspects or features of the Welsh Government proposals, although an appreciation of these reasons would indeed be very beneficial to developing better care for home educators. The relevance for clinicians of home educators' opinions about any such proposals is that, as indicated in this report, they are an **unwanted measure** and thus even more likely to significantly damage the trust-based practitioner relationship, raise barriers to healthy communications and thus impact clinical care.
- In terms of accessing routine health care, such as assessments for neurodiversity or vaccinations, it was clear that parents were keen to access these and were attempting to voluntarily.
 - The obstacles to accessing care were shown to originate either from attitudes of individual HCPs or from systematic shortcomings in referral processes.
 - The requirement in neurodiversity assessments for an understanding of how a child behaves in more than one environment or context need not be an obstacle in assessing home educated children.
 - Intertwining the school system with health care would seem to result in limitations on access to health care for those who choose other approaches to education.
 - It is clear that regulations to identify more home educating families to local authorities are not what is required to address such issues. Governmental policies to mandate identification of home educating families to local authorities would not improve such situations faced by families.
- A sole objecting respondent commented, "*LEAs are doing a great job what are you hiding?*". Alongside noting that the term LEA (local education authority) became obsolete in 2010, this is a useful comment to explore. The presumption and false conflation that desire for privacy equates to "something to hide" can readily influence conscious or unconscious bias. There is a saying in home education circles, "**Nothing to hide but everything to protect**". Responses in this study mirrored this pervasive desire and intent of families to protect children from harm and to defend their education, well-being and self-worth, including protecting their privacy and safeguarding them from the damaging effects of discrimination.
- Apart from the ethical and safety issues in relation to access to confidential health care, other safety issues referenced in responses include the risk of **data-breaches**. Local authorities have been demonstrated to be one of the top offenders for data breaches across the UK, with Wales being identified as one of the worst areas, and with data leaks continuing without lessons seeming to have been learnt. (<https://www.southwalesargus.co.uk/news/19680240.councils-data-breaches-among-worst-wales-last-5-years/>) (<https://www.localgov.co.uk/Councils-among-top-five-offenders-for-data-breaches-/55187>)
- There is considerable risk of inadvertent or inappropriate sharing of data beyond what would be permitted if GP surgeries or other sources of health care are seen as sources of data by LAs. In a recent poll of home educators' experiences of communications from LAs in Wales in relation to routine enquiries about the parents' educational provisions, out of 133 responses, only 4% of respondents indicated that "*all communications received from my LA have*

never had the potential to be misleading, all have been fully clear with no scope for confusion”, with the majority of respondents indicating that they had been asked for more information than was required, and often in a way that gave the impression that it was necessary.

- The Welsh Government proposals on mandatory data-sharing from health care sources for what are stated, at present, as education-related purposes, would not address issues with school attendance, as the proposals assume that education is automatically suitable for any child on the school roll, even if their attendance is 0%.
Rather, they would involve mandating disclosure from GP service contractors and LHBs the identifying data on almost half a million children in Wales (all children of “compulsory school age”).
As the proposals deem the education of children whose names are on school rolls to be always suitable, regardless of attendance or any other challenges faced by these children, 98% of the contact information gathered from GPs/LHBs would then not to be used for those particular databases. However, the potential of this large volume of “residual” data being used for other purposes remains, especially once s29 of the Children’s Act is enacted.
- Alongside safety issues in data handling, many other questions remain, for example, regarding **cost-effectiveness** of establishing and maintaining such databases, including on investigating lawful families, in comparison to established benefits of **utilising funds directly** for children already known to need intervention.
- Further concerns over proposals to mandate non-consensual data-sharing from health care sources include the likelihood of an increasing range and depth of information being requested, in addition to questions relating to management and use of data beyond any originally stated purpose.
 - At present, the consultation documents on Welsh Government proposals to mandate data sharing from health care sources for LAs to investigate educational provision state that LHBs would be required to provide identifying data of ALL children in Wales (name, DOB, address and gender). There is no indication of:
 - why GP surgeries need to be considered data sources if all identifying data is already held by LHBs,
 - what additional purpose GP surgeries are perceived to be desired to fulfil as data providers,
 - what additional data may be hoped for from GPs that is not held by LHBs.

However, the proposals actively encourage LAs to seek out a very wide range of information about children on the databases, such as:

- Contact details of not only primary parent but all adults considered to have parental responsibility regardless of context or history (e.g. regardless of abusive situations).
- Contact details of any person who has care of the child at any time. That is a considerable amount of information without clear indication of where this would be gathered from, and such data would be gathered without consent of those whose details are documented.
- Contact details of any person contributing to even part of the child’s education, without consent of each person, and with this being an extremely extensive list as home education is often a very community based interactive

form of learning that extends well beyond the concept of a small number of teacher(s).

- Details of “*Any additional learning needs that the child may have and any additional learning provision that is called for*”.

(<https://www.gov.wales/sites/default/files/consultations/2024-01/children-act-2004-information-database-wales-regulations.pdf>)

- Furthermore, **if** s29 of the Children’s Act is enacted, the range and depth of data that could be mandated to be provided from health care sources such as GP service providers could readily and rapidly increase, without further consultation, with LAs then enabled to chase up queries with “*local authority partners*” on the grounds that data sharing is now permitted. The potential of data required, whilst claiming to not include medical records, is essentially **whatever details or information that the Minster or Senedd decide to mandate**, seemingly without consultation, specifically:

- “*The name and contact details of any person providing to him services of such description as the assembly may by regulations specify*”.
- “*Information as to the existence of any cause for concern in relation to him*”.
- *information of such other description, not including medical records or other personal records, as the assembly may by regulations specify*”.

(<https://www.legislation.gov.uk/ukpga/2004/31/section/29>)

Given the significant impact of present inappropriate experiences of data sharing on home educators, including how unsafe accessing health care may seem as a result, the likely impact of such widespread non-consensual data sharing on access to health care would be profound.

- The likelihood of non-consensual data sharing causing barriers to accessing health care is a well-recognised phenomenon, with Welsh Government warned of such risks during the previous consultation on such measures in 2020.
 - The creation of obstacles to accessing health care for families by such government proposals must **not** be used to justify any subsequent instigation of monitoring by non-clinical departments of local authorities of families’ access of health care, such as the frequency of contacts of family with HCPs.
 - To create a problem in order to justify increased monitoring of families in relation to that area of life would clearly be unethical.
 - Allowing health care providers to be seen as data-holders for LAs, in conjunction with the inbuilt capacity for markedly increased and as yet unspecified data-sharing that the proposed amendment of the Children’s Act would permit, risks progression to such modes of local authorities routinely monitoring the behaviour of patients.
 - **It would be unethical to introduce the proposed measures with the intent or anticipation of using the resulting detrimental impact on families to justify increased levels of surveillance of behaviour or lifestyle.**

- Correlation of the findings of this research with legal and ethical precedents.
 - We are not aware of any previous study on the impact of non-consensual data sharing or of discriminatory attitudes regarding access to healthcare for home educators in the UK.
 - There are, however, other precedents set regarding this issue and the related principles that validate the findings of this study.
 - (1) The General Medical Council (GMC) response to the 2020 Welsh government consultation on such databases of children based on non-consensual data-sharing from health care sources corroborates the concerns and finding of this report.

The GMC statements in that response included:

 - *“We are concerned that the proposed approach to the disclosure of personal information in the draft regulations is inconsistent with our guidance, doesn’t allow room for professional judgment, and appears inconsistent with the common law duty of confidentiality”.*
 - *“Most importantly, the draft regulations draw a distinction between personal and medical information. **In our understanding, all patient information attracts the common law duty of confidentiality. We don’t set different standards for protecting clinical or medical information and other personal information, recognising the sensitivity of all information that is shared between a patient and doctor.**”*
 - *Requiring doctors to share information about children and young people and their parents **could cause some to disengage with health services**, affecting not only their health but also potentially the health of their local communities”.* The effect would be the same whether it is the GP or the GP admin clerk who does the physical transferring of data, as the source would be the same.
 - *“The regulations would also need to clearly set out what actions may flow from the sharing of information, in order to ensure doctors can be clear with children, young people and their parents, about the nature, purpose and consequences of sharing this information”.*
 - *“We expect doctors to make sure that patients know what information is being shared about them, and to obtain consent to sharing, unless doing so would undermine the purpose of the disclosure”* emphasising the vital importance of informed consent wherever possible if confidentiality has to be breached in specific and individual circumstances.
 - The GMC in that response recommended that instead of the proposals for non-consensual databases of children derived from health care sources, the government instead pursue their goal *“within existing child safeguarding arrangements, which preserve room for voluntary cooperation and professional judgement”.*
 - (2) In 2018, controversial arrangements under which the NHS shared patients’ details with the Home Office so it could trace people breaking immigration rules or falsely claiming state benefits had to be suspended when MPs, doctors’ groups and health charities warned that the practice was “scaring” some patients from seeking NHS care for medical problems. (<https://www.theguardian.com/society/2018/may/09/government-to-stop-forcing-nhs-to-share-patients-data-with-home-office>)

To quote this article on nonconsensual data sharing from health care sources for that demographic group,

- “Critics warned that passing patients’ details on to the Home Office risked turning NHS staff into de facto immigration officers, was **ruining patients’ relationships with NHS personnel and deterring some people from accessing NHS care**. The select committee called for the MOU to be scrapped because it is **unethical and damaged patients’ trust in the NHS**”.
- “In future, Home Office immigration staff would only be able to use the data-sharing mechanism to trace people who are being considered for deportation from Britain because they **have committed a serious crime**”.
- Quotes by concerned stakeholders regarding non-consensual data-sharing from health care sources in that context included:
 - “NHS information should **only be shared in the event of a conviction or an investigation for a serious crime, not to create a hostile environment where people are afraid to go to their GPs for fear information might be reported**”.
 - “We are delighted that at last this shameful sharing of confidential patient information is to end.”
 - The British Medical Association, which was also reported as having “voiced deep unease about sharing of patients’ data”, supported the U-turn on policy on non-consensual data-sharing from health care sources, stating that the former proposals and practice “**fall(s) short of the well-established ethical, professional and legal standards for confidentiality**”.

(3) The recent decision of the Royal College of Obstetricians and Gynaecologists (RCOG), collaboration with various healthcare bodies, to issue guidance to clinicians to **not breach confidentiality of women** who were suspected of illegally procuring abortions was based on that professional body advocating for women to be safeguarded by their data being protected and kept confidential. Even the likelihood of having committed an act that is presently illegal was deemed insufficient to justify breaching confidentiality as it would “not be in the public interest” to do so. In comparison, home education is lawful and not a safeguarding concern.

- To quote Dr Jonathan Lord, who co-chairs the RCOG abortion taskforce and the British Society of Abortion Care Providers: “**A law that was originally designed to protect a woman is now being used against her. We have witnessed life-changing harm to women and their wider families as a direct result of NHS staff reporting women suspected of crimes, and we just don’t think that would happen in other areas of healthcare. We deal with the most vulnerable groups who may be concerned about turning to regulated healthcare at all, and we need them to trust us**”. Dr Lord was reported as saying he believed some NHS staff had shared information with police because they were “**ignorant**” about confidentiality regulations.

(<https://www.bbc.co.uk/news/health-68036171>)

The parallels to the impact of breaching confidentiality for home educating families are clear.

(4) The “Named Person Scheme” in Scotland, which would have seen a named person – usually a teacher or health visitor – act as a clear point of contact for every child from birth until the age of 18, had to be withdrawn following ruling at the UK Supreme Court that “*the proposals around information sharing breached the right to privacy and a family life under the European Convention on*

Human Rights” with the proposals meaning that “*confidential information about a young person could be disclosed to a ‘wide range of public authorities without either the child or young person or her parents being aware’*”

- (5) In 2010, a safeguarding database of children had to be abandoned and the database shut down, having been heavily criticised by a wide range of groups for privacy, security and child protection reasons. That database had been based on the English equivalent within the Children’s Act 2004 of the s29 being used to justify the present Welsh government’s database proposals. Amongst many other organisations and groups, the BMA had objected, not only because of implications of breaching patient confidentiality, but also in that case of risks of breaching data protection law and leaving NHS trusts open to legal action. Auditor reports had found that such a database could never be secure.

(https://assets.publishing.service.gov.uk/media/5a74881ce5274a7f99028f07/deloitte_20contactpoint_20dsr_20report.pdf) via this page

(<https://www.gov.uk/government/publications/contactpoint-data-security-review>). The database was criticised by the then Deputy Prime Minister, Nick Clegg, as being “*outrageous that decent, law-abiding people are regularly treated as if they have something to hide*”, further commenting that, “*We will end practices that risk making Britain a place where our children grow up so used to their liberty being infringed that they accept it without question. There will be no ContactPoint children's database*”.

(https://en.m.wikipedia.org/wiki/ContactPoint?fbclid=IwAR2xjrMSNAVIstqV2nAc_INNDuHEOowBj73lCbm_vODbjthQ1Qi6JWtODGw)

(https://www.familylaw.co.uk/news_and_comment/contactpoint-database-to-be-scrapped)

(<https://www.theguardian.com/society/2003/oct/29/childrenservices>)

2.5 Conclusions:

Whilst the findings of this study may readily be seen to relate to clinicians, it is also fundamentally relevant to those that represent them and those that coordinate health services, such as local health boards, to enable all to fulfil the role of protecting and serving patients and to help ensure that all staff behave respectfully, honourably, appropriately, ethically and lawfully.

Widespread non-consensual data sharing from health care sources may be portrayed by some as a safeguarding measure, in order to identify groups of the population who MAY, for example, not be in receipt of a suitable education, who may not have registered with a GP or dentist, or who may not utilise these frequently. However, such wide-reaching attempts at data-harvesting are neither reasonable nor proportionate, especially when they are demonstrated to be likely to do harm in the process. Confidentiality extends not only to what patients tell clinicians, but the very act of accessing or registering for health care is confidential in itself. Breaching confidentiality on **all**, to potentially identify a **few**, when the measures to do so have been demonstrated to risk damaging **many**, is not reasonable or proportionate. It is akin to taking a sledgehammer to crack a nut, risking damaging the wellbeing, education and access to health care of home educated children in the process.

Inappropriate and disproportionate data-sharing is counter to human rights and would also infringe a range of articles of the UNCRC; more information can be provided on this aspect if required.

However, for the purposes of this study, the relevant findings and conclusions are that in individual conduct, in departmental protocols and in governmental proposals and policies, the fundamental principles of confidentiality and informed consent must be respected **at all points of the service** when engaging with families who exercise their lawful right to home educate in order to protect both the wellbeing and access to health care of home educating families and the integrity and professionalism of HCPs.

2.6 Further research:

- Future research would be beneficial to explore the content of training programmes delivered to HCPs, in particular training on safeguarding issues and on the ethics of confidentiality and informed consent, to document how elective home education is presented to HCPs.
 - Such research could establish if there are cases or trends in the information or attitudes in HCP training programmes and sessions that conflate issues safeguarding and EHE, investigating whether training portrays EHE as a safeguarding issue or whether it accurately informs HCPs of appropriate conduct.
 - There have been individual accounts to HEACH reporting training sessions for health visitors and for midwives where staff were instructed that EHE was a safeguarding concern that needs to be reported. Further evaluation of the content of training sessions for HCPs where EHE is referenced, and of the prevalence of any such dissemination of misinformation, would be beneficial in progressing beyond false connotations and in protecting children from discrimination and stigmatisation and in ensuring families are allowed open access to optimal healthcare.

- Further research into the understanding and approaches of HCPs could be useful.
 - This would, of course, be extensive research given the wide range of types of HCPs.
 - However, unconscious bias on the part of HCPs would be likely to be a confounding factor in the responses to such a study, with the potential responses of concepts not necessarily reflective of how communications, attitudes and conduct are experienced by patients.
 - Research that focusses on the effects of interactions on patients, rather than the way HCPs may have perceived them, would seem more likely to be relevant in understanding the deterrent effect on patients.
 - A survey of various HCPs' understanding of home education may be interesting to inform better training.
 - However, that could be of limited relevance when the need for improved understanding and training has already been demonstrated.
 - Furthermore, respondents have also indicated from their experience that it is not so much the amount of accurate knowledge that can be problematic but rather the willingness, or lack of it, to hear and learn from patients' and families' experience.

2.7 Recommendations based on this study in conjunction with legal and ethical precedents:

1. Improved education and training of HCPs and development of respectful, lawful and informed policies by health care services in relation to elective home education.
 - Professional bodies who represent HCPs have a vital role in disseminating accurate and mutually beneficial information and advice in relation to home education.
2. Such education and training would require the input from experienced home educators, from those with lived experience of the issues being addressed, to ensure any discriminatory attitudes to are not perpetuated and that information is conveyed correctly and constructively.
3. Development of government policies founded upon, and then developed under, the guidance that can be provided by genuine, open and meaningful engagement with those with lived experience of the issues.
4. As with the 2018 U-turn on health care sources data-sharing of those suspected of breaking immigration and benefit rules, government policies that inhibit and place obstacles for families seeking to access health care, and which mandate non-consensual data sharing of certain demographic groups, must be abandoned.
5. To follow the advice of the GMC, and to reflect the insight, experience, concerns and wishes expressed by so many respondents, respectful and voluntary approaches to engagement with communities such as home educators would be recommended.

3 Collation of free text responses demonstrating personal experiences.

This section contains a representative collation from the many free text responses to illustrate the main trends, issues and experiences noted. These are included, sometimes with more than one quote to illustrate each issue or experience, not only to verify the summary below but also to enable the reader to appreciate the perspectives and experiences of so many home educators, to enable reflection on their own practice and to understand the powerful nature of the impact of such experiences on access to health care. Relevant challenges faced are highlighted to facilitate ease of reading.

3.1 Responses to Question 3g:

This free response question asked:

Please share more information below about your experiences if have answered yes to any of the preceding questions.

That is, please share your experiences of any:

- misleading or false information you were given by a health care member of staff
- comments/indications that they did not understand either the legal aspect or everyday practicalities of/approaches to home education,
- impact on your relationship with a clinician or department, including in being able to maintain a trusting relationship,
- situation where you felt pressurised by a health care services member of staff to not home educate your child, or to send them to school
- situation where you felt that they considered home education to be a less valid approach to education than school-based education?
- impact on health care provided.
- other relevant comments.

This information can be very useful in anonymously conveying the experience of home educators.

However, please remember that anonymised data, including some quotes, will be shared as explained in the introduction, so only share in a way that protects your family's privacy.

These selected quotes, taken from extensive submissions from respondents, illustrate:

- Not all encounters home educators have with HCPs are bad or course - but what makes the difference?

- Examples of HCPs not understanding legalities of EHE.
- Examples of inappropriate data-sharing without consent from health care sources purely because home educated.
- Examples of HCPs not understanding how home education works and functions.
- Examples of institutionalized discrimination (including false conflation with safeguarding).
- Examples of difficulties for home educators accessing health care due to negative, ill-informed or discriminatory attitudes within health care provision.
- Examples of lack of understanding by HCPs of school trauma.
- Examples of HCPs expressing negative personal opinions about EHE to parents.
- Examples of HCPs expressing negative personal opinions or demonstrating discriminatory attitudes directly to home educated children.
- Examples of damage to practitioner patient relationships.

Collated and selected responses to question 3g, in relation to

Encounters can be positive, not all accounts are bad.

The first thing to note, in light of the accounts that follow, is that not all encounters that EHE families have with HCPs are bad, neither do all HCPs hold or convey negative attitudes towards home education or overstep professional boundaries in relation to EHE.

*“Our experience with doctors has been just the opposite. All the doctors we have encounter have seen it as **positive** and interacted with my son as the intelligent well-articulated young man he is, and they have **commended** how well home Ed is doing for him. ”*

However, it is of note that those who mentioned they had not had negative experiences often also commented on **strategies they had learnt to employ to deflect attention or unwanted comments and questions** in relation to their choice of educational provision when attending appointments with HCPs.

*“I haven't experienced anything, but this is only due to the fact that I've **never told** anyone in health care that I'm home educating. It may or may not happen in my area, I just **haven't given anyone the opportunity to react to it**”.*

*“I **wouldn't admit** to local GPs we use that we home educate, but when in hospital with my youngest I **didn't mind disclosing** it, feel like attitudes in the city were different (plus we were out of our LA then due to it being a specialist hospital)”.*

*“To be honest I've never had an issue. Our youngest has disabilities which pretty much make him incompatible with school. and all medical appts have been fine and they even agree he's doing better out of school and schools often fail kids with his disabilities. I tend to be bright and breezy and then **deflect** when medical people question us and to date it's worked well as a way to deal with nosy questions ...I am cautious in case they are prejudiced against home edders in general”.*

Others commented on how they felt that **maintaining an appearance that did not reinforce connotations of prejudicial stereotypes deflected** the expression of unhelpful or discriminatory comments.

*"I don't like the idea of info sharing, its abhorrent. We have probably been lucky as we are **white, married, middle class** and I know how to confidently communicate with professionals so **can brush off their questions** with a, "Yes, we home ed and our child is doing really well - now about that scan/ next appt etc...". We have had questions for years now too, so I guess I don't bat an eyelid or get confrontational or panic, and also I **don't overshare** either when it's none of their business. I also go to medical appts armed with lots of questions so I would rather talk about those and **deflect back to the topic** we are there to discuss.*

Although others may feel some exasperation and frustration at the need to be frequently educating others regarding home education:

*"I do not feel it is my job to have to have **educate** medical staff on areas that are **not even in their remit**".*

"Had I not known the law so much and could see how their obvious biases, was affecting the questioning, and the medical appointment. I think there would have been different results ... medical staff cannot be in charge of sharing information they do not understand, it brings stress for the families and massively oversteps the right to a private life. If a genuine concern, I would be happy for them to share safeguarding issues".

The difference between positive and negative encounters seems to be not only the initial experience or knowledge of the HCP but more importantly the **willingness of the HCP to listen to the parents** and find out more about home education in a non-presumptive or non-judgemental way, plus a **willingness to change their opinion or approach** once they had gained more insight or understanding.

*"I was told by our health visitor that I should have registered our (older) child with the local authority when we deregistered her from school, though to her credit she **accepted my correction on this point** and made a note of it for the future".*

*"My child's developmental paediatrician insisted on spending most of each appointment discussing her concerns on home education. It impacted our working relationship with her. No other professionals involved in my child's healthcare had any concerns at all, but this particular doctor seemed **unwilling to really listen to my answers to her questions**".*

*Even if there is no overt negative outcome or communication from such encounters, they can still be **unsettling and potentially stigmatising** for families,*

*"On a separate occasion, I was visiting the optician with my daughter, and when asked which school she attended, we responded "home educated". She then said, "Oh, I'll have to go and check something with someone", and she went off for a few minutes. We felt quite **uncomfortable, as we did not know what might happen next**. Thankfully, nothing happened, but it was weird."*

*"Other clinicians I have met, whilst not having any great understanding of home education and possibly initially holding some mistaken attitudes, have been **more open minded, leading to mutually beneficial and constructive conversations and positive relationships**. I don't mind if clinicians or any other staff don't know much about home education, I didn't once upon a time, but what makes such a difference is a **willingness to learn about something that do not know much about, versus a closedmindedness**, prejudicial attitude and presumption that know better about something that have no knowledge or experience of that have met in some clinicians and staff. As home educators we do meet such closedminded or paternalistic attitudes sometimes, sadly usually from those in officialdom, such as government, but the effect of such attitudes is **particularly damaging if they are held by those involved in clinical care** as the relationship of openness, trust and respect between clinician and patient is so fundamental and essential".*

*"I could tell our health visitor **didn't approve of home education**. I think she'd forgotten about us, even though our little one had some significant health issues, but to be honest that was a lot easier, it was a relief when she seemingly forgot to call or contact us. She once phoned to ask our plans for education for that child when he*

approached CSA, with us having not seen her for a long time. I was **deliberately vague** as I did not trust her to not disclose any plans or intentions to the LA. If we had met with a **healthier, more openminded and respectful attitude** we would have been more than happy to discuss our plans including the reasons for our choices, but as we **could not guarantee that these would be held in confidence or that they would not be used against us** in some way to make our lives more difficult than already were, then we knew it would **not be wise to engage in communications on this issue**".

Examples of HCPs not understanding legalities relating to EHE

Several respondents reported being told by HCPs that home education was either already illegal or that it should be.

For just one example, "I have been ...told that home education is **illegal** by a nurse".

Several instances where HCPs thought they "had" to tell others that the family were home educating (eg had to tell school nurse or LA if they encountered a home educating family).

"I had a letter from the dentist saying **if my child missed an appointment, they would 'have' to contact other healthcare providers**".

"... **whispered** about it yet **in front of me** with **concerned expressions** clearly discussing if they should report the family for safeguarding because the child didn't go to school".

"The health visitor **not only shared my child's personal information with the local authority when my child was under CSA on the basis that I was considering home education for when she would be CSA, but also gave me misleading information** such as I'd have to register with Ofsted, that **in her opinion I'm potentially abusing my child with my decision because she didn't agree with my reasons** for considering home education and also **tried to claim that home education would be a basis for contacting social services as its a safeguarding concern from her point of view**".

"A GP I met on the bus asked why the children were not in school. When I explained she checked that we were registered. I explained that this was not necessary. She said that she is a GP and would always check if home Ed children are registered. I explained that this was a **breach in GDPR, and she insisted that safeguarding trumps GDPR**."

"My health visitor had **no understanding** of Home Education and thought it was **illegal** and **reported it to the LA** who had to inform her otherwise, as she did not believe me. My home educated child was already far ahead of mainstream educated school children, and was **safe, happy and healthy**."

"Paediatric nurse informed me that home education was a **'known risk factor'**".

"Several hospital doctors have asked us if we are on the local home education **register**, though **no such thing exists**".

"Health visiting team **informed local authority** we were home educating, leading to the LA requesting they pass on details. LA informed health visitor that I had to call LA. I informed health visitor I had no such obligation as my child has never been enrolled. This **undermined trust in health visitor** as they **clearly don't understand legal situation**."

Examples of inappropriate data-sharing without consent purely because home educated:

"I was visited by a health visitor after giving birth and had a post-natal check with my GP. I was questioned

regarding home educating my older children. I was not known to the home education team. The health visitor told me I had to inform the home Ed team. The GP **questioned me about my children's academic abilities**, and I **didn't feel she was interested in my post-natal check**. I **felt interrogated** by the GP on my children's academic abilities. After this a few weeks later, I was **contacted** by the home Ed team by phone and told they were the **safeguarding team**. **Neither professional said they would be contacting the home Ed team**".

"My child needed to attend A&E and the nurse there said due to them being home educated, they **must refer him to social services**. When I questioned this, they said this was **mandatory**. I got a call from a local nurse approximately one week later, who requested an update on my child's recovery. Although I didn't hear from SS this has **damaged my confidence in NHS services** and know now that any health official could **refer to SS for no other reason than EHE**".

"After one experience at A&E with my eldest we were **doorstepped** by the LA a fortnight later."

"...Child psychologist, **pressurising into going to school**. Even **tricked** into having a one-to-one chat with our eldest and then **reported us to early help**. They are **amazing**, however. They **knew us from before** and they **knew it was a malicious report** so gave them a good telling off. "

"I have a daughter with physical disabilities. The consultant asked which school she would attend and made comments about **socialisation** when we said we were intending to home educate. He was not supportive. I **agreed to him contacting the LA** as we would be seeing him regularly and I **didn't want to antagonise him**. I felt he had **no knowledge** of home ed and was dismissive. I **didn't feel I could challenge him or refuse let the LA know....He definitely contacted the LA**"

"A health visitor made me **feel very uncomfortable** about the fact that I was home educating, and she **insisted she share my children's data with LEA** - even though I told her I had already contacted the LEA to inform them I was home educating, and **even though I told her I did not wish her to pass on my children's data**".

"New health visitor phoned to introduce herself after birth of 6th child. Enquired which school older children attended and I said they were home educated. She **got very angry** and said I **couldn't possibly look after a new baby properly whilst home educating**. Left me very upset. **Half an hour later I got a phone call from LEA to say they had been informed** we were home educating. Previously we had not been in contact with them.

"The **SALT lady referred us to social services** when we first started home educating because ***she felt*** home education wouldn't be suitable to meet her special needs and **allowed her personal opinion to cloud her professional judgement** resulting in a referral. This referral was that I would be ***Home educating***. Case was closed down due to no concerns because home education is not a safeguarding concern ... Was done by teacher and SALT through lack of understanding of Elective Home Education but **took a while due to manipulative behaviour by the professionals involved**. Case has now been closed for six and a half years.

"When we first sent in the deregistration letter to the school we were deregistering from, the Headmaster and **SALT referred us to social services** who then opened up a case due to me 'home educating' *****. Clearly, they **did not understand that Elective Home Education is not a safeguarding concern** in itself and thus making such a referral wastes social services time... The case was closed with no concerns. However, this now means I'm very wary of health professionals because of **lack of understanding** about EHE and because of their position are able to **share information without my consent behind my back**, which has **resulted in some degree of distrust** in myself towards these professionals.

This has **improved recently with me positively engaging** with my doctor. However, my concern is that many health professionals **do not understand** the full scope and variety of home education and likewise, thus make **unnecessary referrals**, and/or make **comments/take actions which impact the home education community in a negative way**.

If interactions are to be more positive, they need to be properly **informed** and treat home educators with **respect**. This is not **going to happen if they share all/any information about our children without consent**. Furthermore, this **interferes with parental responsibility, our rights and our children's rights. It breaches GDPR, it scars the interactions of home educators with the health board and health care individuals not because we have anything to hide but because we are being treated as if we are a danger to our children**. It is the wrong approach to seek when they are wanting to adopt positive interactions with the home education community and worse it could cause ...home education families to **disengage** with medical professionals, the absolute **opposite** to what they are trying to achieve."

"My daughter was in intensive care after brain surgery and the hospital school turned up with a form saying I had to sign it and my daughter had to go to the hospital school and they would come to her bedside. The nurse **referred me to the hospital school without my consent**. I was then **reported to social services** who had a meeting and told me I **need** a sick letter from the hospital if my child was not in school, **claimed I was neglecting my daughter's education even though they don't know what my provision is**".

Examples of not understanding how home education works and functions:

"Generally medical staff have **assumed home education is replicating school at home**".

"My GP initially informed us we **could not access** the school nursing team".

"I've been asked several times which **curriculum** we follow or if I'm a qualified **teacher** (home educators don't need to follow a curriculum or have any particular qualifications and it concerns me that perhaps those who don't could be **judged adversely**)"

"Dentist (we had to pay private) asked what my **qualifications** were **if I felt** I could educate her myself".

"Health Visitor clearly had **absolutely no idea** what home education means, told me that I couldn't home educate without a teaching qualification".

"Health Visitor had **absolutely no idea** about the right to home educate or what it involved. **Constant use of incorrect terminology and misunderstanding**.

"CAHMS nurse at initial assessment, on learning son was home educated said, "He **needs to be in education**". I replied, "**He is.**"

Paediatrician thought that home education was an awful lot to take on for a parent and asked if had help from the LA to deliver the **NC**. I laughed and advised that we don't have to deliver the NC. The paediatrician wrote into his report on son's hypermobility, under parent action, that we should 'stay in contact with LA and Sendiass for support.'

"Have had staff members **assume** home ed has to follow the national curriculum, assume that we have to do termtime and holidays, felt like I have to **justify** it by adding 'it's still possible to do GCSEs/go to university and I'll always let them choose if they want to go to school' as sort of brushing it off as a 'weird' choice we've made."

"Health visitor who repeatedly stated that home educators are funded and given educational guidance by the government/ local authority **despite being told otherwise**".

"Consultant then started talking about the need for **socialisation** of our child, which caused me to feel a little **frustrated and patronised** although the consultant was **well-meaning**".

"I find professionals expect you to do **traditional** learning like workbooks and reading books. I find they see home education as a **safeguarding risk**".

*"I was told by a GP I **couldn't** Home Educate as I'm not a teacher... (I am actually qualified to be a teacher however that's not the point)*

*I was told by a health visitor that, because my son has SEN, he **won't thrive or learn** being home educated. I was told my Speech and language that unless I enrolled my son into school, I **wouldn't be able to access an EHCP**".*

*"Paediatrician put down, **'Homeschools** her child' on form and files. I had to correct this... (Respondent is referring to incorrect use of terminology by paediatrician referring to electively home educating as 'homeschools'.) "He also had the idea that EHE was somehow **school at home**, and expressed, 'Doesn't someone come in and assess her learning?'" (Home educators are often keen to ensure the use of appropriate terminology to reduce the inference from the term "homeschooling" that EHE is a form of 'school at home').*

*"Receptionists **refusing to give appointments** for a home educated child 'during the school day'.*

*"We experienced a **horribly discriminatory attitude** towards home education from an NHS occupational therapist. Her tone and comments revealed a tone of **despising and sneering** that wasn't even particularly disguised. It **clearly influenced her assessment**, she didn't even accept the information questionnaires we'd been sent to complete, and there were the occasional snide comments to my son when assessing him about what he would be able to do, insinuating that he didn't really have any needs and that we as parents were somehow at fault. She **belittled** his needs and his difficulties and did not arrange any intervention or follow up. We had waited years for this appointment and were desperate for help and intervention. Her report letter contained inaccuracies, including **mistaken assumptions**, including stating that he needed more socialisation - (she had not asked anything about socialisation during her assessment and her **presumption was incorrect** as my son had a very active social life with a great network of supportive friends). I should have challenged her attitude and report with a formal complaint, but to be honest I was so upset and angry at such discrimination I simply **could not bring myself to write the (complaint) letter**, especially as we were left to try to continue to meet our child's needs without the help we had sought and so our time was filled trying to do so. We **used savings to pay for a private occupational health assessment** and met a completely different attitude and approach, we were given a constructive plan of management but were unable to afford many further appointments privately. We were left without NHS input for his needs due to discrimination and ignorance and had to do our best to meet his needs alone. It **still troubles me that such a discriminatory and inaccurate report is in his medical notes**".*

Examples of institutionalized discrimination (including false conflation with safeguarding)

*"When I asked why my GP application form put a request for information about home education on the generic form, and why it was **under child safety and not education**, the receptionist was clueless. It felt like it was considered a **safeguarding issue**. "*

*"I work in the NHS, as well as home educate... I have also read safeguarding **reports** that are published by local authority and NHS (sometimes other agencies too) that have a **disparaging view** of home education..."*

*"Nurses/ receptionists at a hospital couldn't proceed with booking one of my children into hospital without stating which school they attended. They **literally couldn't move on with the forms**. They **asked me to lie** and state my child was in school to complete the form. In the end because I wouldn't lie, they **made a school name up** on the form."*

*"Whilst waiting for an outpatient appointment, a nurse asked me to complete a form before my child was called in to see the consultant. Only after I'd started filling out the form, and had questioned the section regarding sharing of information with the LA, did she inform me she was a **"safeguarding nurse"**...I informed her that I was happy for information to be shared with her healthcare team at the specialist children's hospital (where 99% of her clinical appointments and treatment take place) and also her GP, but I **expressly refused permission for***

information to be shared with the council. I wrote this information on the form, very clearly. The form asked about my child's education and provided the options of in school or "home schooled", which I corrected to 'electively home educated'.

*The safeguarding nurse informed me * ***** had a **blanket policy of sharing the information of all 'home-schooled' children with their LA for safeguarding reasons because 'these children are not seen by professionals'.***

*As a family that has considered the children's hospital to be our second home for the past eight years, we were **horrified by the hubris and ignorance** of this comment, as well as **horrified by the complete disregard for our child's right to keep medical issues confidential.** By sharing our child's data, the LA now knows there is an involvement with that hospital. **We feel violated.** There has been absolutely **no mention of specific concerns that would warrant sharing our child's data without consent.***

*A few days later, I received a phone call from the same nurse. She explained that the safeguarding lead at the hospital was sticking to the ***** policy and my child's data would be passed to the LA on the basis of **"implied consent"**. I requested that a written version of this **blanket policy** be posted to me, but she informed me that I **probably wouldn't be allowed to see it.***

*A few days after the phone call, an employee of the LA, a Children Not in School caseworker, **attempted to doorstep** us and left a note. I found this particularly strange considering we were open about home educating. I emailed a **complaint** to the Information Governance Manager of the hospital ...but have **not received any acknowledgment**...I have **not received any communication** from the safeguarding lead, because apparently she **only likes to talk on the phone and not put things in writing** (as I requested)."*

*"When our daughter had an Asthma attack, we rushed her to A&E. Instead of getting our daughter support to breathe, we were taken into a little room and **treated like criminals.** Lots of questions about Home Educating."*

*"We have been very fortunate that both our surgery and dental practice are quite **enthusiastic** about home education, and we have not had too many issues with our local hospital, either. However, our local hospital does have a **disturbing policy.** If you announce/admit that you are a home educator, the hospital staff member (admin, nurse, doctor, midwife, etc.) filling out the forms/adding data about your child, **automatically asks if your child has a social worker or has been in Care, whereas this is not asked if your child is nursery age or below, or if your child is school-age and attending a school. The conflation of HE and safeguarding is scurrilous...**"*

Examples of difficulty accessing health care for home educators due to negative or discriminatory attitudes of HCPs towards EHE, including the focus becoming home education rather than health care issues.

*"Child **hasn't been given an epi pen** for peanut allergy because we home educate so he **'won't need one as we're always together'**".*

Some respondents reported difficulties with or refusals of referral for assessment of **neurodiversity** unless the child was in school, being told that it was essential that a teacher provided evidence as well.

*"Asked the health visitor about concerns regarding neurodiversity and was told that it was because our son was at home **being spoilt by 1:1 attention** and that was the problem".*

*"I was told we **couldn't get assessed for Autism/ADHD** due to my child/ren not being in school."*

*"Was told **wouldn't be able to proceed with autism assessment** unless in school."*

*"**Wouldn't be eligible to have an autism assessment** unless in school."*

*“A past paediatrician made me feel as though I was doing a **disservice** to my child by home educating them and that they would be **better off in school** and went so far as to indict that they thought many of the difficulties my child was experiencing (because they were undiagnosed Autistic, PDA and ADHD at the time) **would not be present had my child been in school**. I had to **fight for a referral for an assessment** for Autism and even when one was made, it was **turned down** as my child was home educated and they would only take on a referral if they had involvement from the child's place of formal education. Therefore, my child was **denied an assessment and diagnosis and thus, any help or services** available to a child with a diagnosis just because she was home educated. We had to **wait until I was able to save enough money for a private assessment**, at which she was diagnosed Autistic with a demand avoidant profile which obviously had been the issue all along and not the fact that she wasn't in school at all.”*

*“The paediatric psychiatrist who assessed my child for neurodivergence told me he **preferred children to be in school** and that the assessment would be more difficult without school attendance. He said **my child 'should' be in school** and that it would be **better** for my child. Once my child was diagnosed with ASC, he said if s/he went to school, help would be available, but **if we continued to home educate there wasn't any available to us**.*

*“Paediatrician **refused a referral for ADHD assessment** because 'we can only accept a referral from a school SENCo, so child would need to be in school for a referral to be made'.”*

*“The GP had **no knowledge** of how to refer my child when I queried if they had ADHD. It took some time for them to determine where to refer me. In retrospect I was probably **not referred to the correct place** meaning that the contact with nurse who I was referred to was delayed by 7 months. The nurse who we saw initially from the referral was **condescending** in her attitude showing that she had **no knowledge** of home education”.*

Other home educators reported experiencing difficulties in finding somewhere to have their children **vaccinated**, not because there is not provision in place (EHE families can and do access vaccines through GP surgeries or school nurse teams) but because of negative and prejudicial attitudes and/or lack of understanding of EHE by HCPs making access to these difficult.

*“We have been **told by professionals** that my primary age child **could not have his flu vaccine due to not being at school which is false**, my GP **refuses to help me with an ADHD diagnosis** for my child because they do not go to school and also **berated me** for choosing home education and told me the council should be sending me the curriculum and should be helping me (I didn't ask for help with home education) which goes to show they **know nothing** about home education.*

*“**Dr Refused vaccinations** stating that our daughter should have them at school.”*

*“A nurse **told me my son should be in school instead of at home** when I asked how to get a flu jab for him, and I was **not able to access the flu jab**.”*

*“I was told my child **couldn't have the flu vaccine** unless it was in school by the school nurse. Even though it was being given to my then 3-year-old at the surgery, **they refused** it for my 5-year-old as he wasn't at school.”*

*“I was told by a health visitor and midwife that my children **wouldn't be able to receive services that schooled children receive (eye exams etc)** because my children were to be home educated.”*

*“Have found it **increasingly difficult to access flu spray** for my 5 year old without disclosing education info due to fear of being reported to LA (we are currently unknown) ... (luckily have managed to get it annually but it's always a concern).”*

*“We have chosen **not to use the home school nursing service** as we were **not confident that our daughter’s details would not go to the local authority.** We always use our **GP instead for vaccinations** etc. This has resulted in **not taking up flu jabs** as they were only available through the nursing service.*

*“**Lack of access to routine vaccinations** led to being **interrogated** or reflected as a safeguarding issue when accessing medical treatment, therapy, even eye tests caused debate about funding for prescriptions as couldn't reference school although under 16 at the time”*

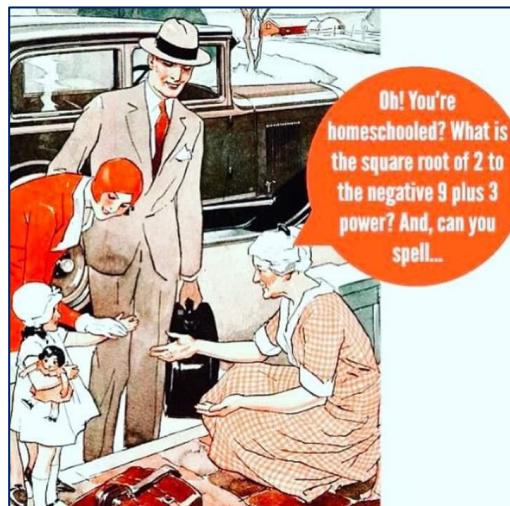
*“I called to **request a flu spray** for my child, the receptionist told me this wasn't an option at the GP practice for home educated children and that we will be 'mopped up' once the schools had been vaccinated. Unsure how this mopping up would happen I questioned further only to be told that she didn't know and that they wouldn't be offering my daughter a vaccination at the practice.*

I then contacted public health Wales who responded quickly, within the hour I had phone call from the practice manager offering a vaccination and an apology.

Each year I call I have to remind the reception staff that public health Wales agree with me that the children do have their flu vaccination at the practice”.

“During an A&E visit, doctor presumed that my daughter was not vaccinated just because she was home educated”. (incorrect presumption, child was vaccinated)

Some reported that the focusing of the HCP on the fact that the child was home educated meant that the issue about which the parents had sought medical care was no longer the **focus** and was not adequately addressed, if at all.



*“...Paediatric consultant... felt that my daughter’s fatigue was down to her sedentary lifestyle being home educated. She kept pressing the point that she’s not walking to/from school or around school so therefore not getting any exercise. This was despite my saying she goes for walks. Now we have moved away from that area and new paediatrician didn’t bat an eye at the fact we home educate, but instead has looked at her Vit D and iron levels, which are very low and contributing to her fatigue - not the fact that she is home educated. I felt that the **standard of care we received was much lower because of that first paediatrician’s fixation on lack of exercise because of being at home.**”*

*“Mainly, health care professionals start to ask questions about home education in general. This isn't always a problem but largely you want them to **focus** on the reason you are there for treatment. It's **hard to feel you***

have to justify your educational decisions when your child just needs medical help. It's not the best time to discuss the benefits or difficulties of home education."

*"Doctors and nurses being **more** interested in the fact that we home educate rather than providing clinical care. Nurses spending time **quizzing** home educated child about their education, rather than attending to clinical care of parent who was the actual patient. Similar things have happened when the child ... was the patient.*

*"The Health Visitor was so **unhelpful and dismissive, plus inattentive** for the purpose she should have been there for, I declined her further visits, as I felt her presence was **invasive, unhelpful, and intimidating**. When my third child came, I **declined** a Health Visitor due to my previous bad experience."*

*"Physiotherapist was **more concerned to about how we were educating our granddaughter than doing any therapy** for her."*

*By a home educating parent who was taken to hospital in an ambulance with acute breathing difficulties: "The paramedic saw my son sleeping and **questioned me heavily in the ambulance....** Why doesn't he go to school?How is he ever going to get a job? ...Thankfully her colleague was more understanding but **when you can't breathe you don't need this judgement or questions**".*

*"The doctor and the nurse wished to discuss this at length **rather than deal with the matter of the appointment** which was for an ear infection that my daughter had to sit there in pain with whilst we were questioned about her education, it was **immensely unprofessional**, there was **nothing that could have given them cause for concern to warrant questioning and also delayed access to medical care which is their primary role**. To be questioned ...**in front of my unwell child** on matters not relevant and having to defend our education provision was **immensely overstepping the mark**."*

*"My child has many health difficulties and so one of the reasons we started home educating was so that we could more easily work around all of the medical appointments. Pretty much every time, we would get asked about which school my child attended and sometimes only saw confusion and frowning, but often staff would **feel it was their place to tell me that my child should be in school and they (the NHS) would do all they could for my child to return to school. Not do all they could for my child to not be in constant pain...**"*

*"When visiting a GP with my eldest, most of the appointment was spent **scrutinising our decision** to home educate and **telling us why we were wrong**. It was **utterly irrelevant** to the purpose of being there and we have **requested to never see this particular GP again. It is incredibly off putting and unnecessary. It leaves you anxious** about accessing medical professionals as they decide to give **unsolicited and ill-informed opinions and have the potential to make life incredibly difficult**. This is both **unfounded and ignorant**. It is an **absolute pleasure when you meet a medical professional who respects your choices as you're then able to access what you need as you open up**".*

*"I've stopped taking my child to her NHS dentist and **instead pay privately** for her dental care at my own private dentists. Her NHS dentist had made a fuss on each visit about home education and why I felt that's the right decision for my child, and I felt was **conflating** my daughter's oral care needs (her health conditions and medications have an impact on tooth/ gum health) with her being home educated. I was too uneasy about her attitude to continue attending.*

*In contrast I have had **supportive comments** from her optometrist, and our GP has always been **both interested and relaxed about it**."*

*"The attitude and reaction when told the child is home educated is **not positive**. They made it look as though home education is a **lesser form of education**. Some are not respectful of it and will **pass comment that can sow seed of doubt in the child's mind** as to whether their parent's choice is good one for their lives and future"*

*"Opticians **refusing to give free NHS eye tests** to a child who is home educated".*

*"I have **declined** to get follow up blood tests or appointments (for the parent) following **intensive questioning and a very negative response** to the fact we home educate by a GP. I didn't want to have to go through the experience again and just **hoped I'd get better on my own**. The impact of these experiences is that we now **avoid mentioning** that we home educate to medical staff and no longer allow our child to accompany us (parents) to our medical appointments."*

This quotation helpfully demonstrates the impact of discriminatory attitudes on the health of parents/other family members, and the barriers it places to communication and to access to healthcare".

*"GP was **not aware** at first that **referrals** to CAMHS could go through GP and tried to insist my child needed to be registered with a school.*

CAMHS initial assessment team was perplexed as to how they should proceed as they had no school to liaise with. They insisted on contacting previous schools.

*This resulted in **no support from CAMHS** and **eventually going private** for mental health support."*

One respondent indicated a chain of difficulties from NHS occupational therapists team in relation to a lack of understanding of home education, culminating in a sense that "*they'd closed ranks*", resulting in needs not being addressed, then describing how instead, "*with the **support/encouragement** from our privately paid OT*" the family were able to (privately) source other assessments and find management, therapeutic and educational options that have enabled the child to flourish.

*"Getting **access to diagnosis** for mental health and ASD /ADHD and similar services for home educated children is disgusting and discriminatory. No teacher on this planet knows a child better than a parent and to **deny** these children the time and assessment they need just because it can't be recorded in another environment is shocking! I have **had to go private** for both of my children for ADHD and ASD because **CAMHS wouldn't accept them** as they wanted teachers / classroom reports".*

*"When our daughter suffered from anxiety due to school bullying and discrimination for being dyslexic, I was worried about her. I took her to the doctor and **all this doctor told me was that our daughter had to go to school**".*

*"Consultant and GP **expressed dislike** of home ed and it being worse than the long list of medical issues including life threatening ones! **Refused to progress health care** as not in school so **had to go private**".*

*"A nurse at the same practice **repeatedly asked** why the children attended an appointment during school hours and not wearing a school uniform. I had been questioned previously by another member of staff, I informed her that we home educated the children and she proceeded to ask questions about who knew that we were doing it and would we continue beyond primary age, it **felt uncomfortable as we were there for me to receive medical advice in no way relevant to this**. I am **always open to the discussions** around home education as they do happen a lot, but this **felt beyond curiosity and made me feel uncomfortable**. "*

*"I had just had a baby and had a home visit by the midwife. My daughter was in the other room doing her work and came in to ask me a question. The midwife then asked why she was at home doing work and she replied she's home schooled. Her attention immediately turned to my daughter who was, healthy, dressed and washed, actively engaging in conversation and answering all her questions, rather than the new born baby she had come to see. She asked **condescending questions** such as didn't she like school and what she likes about homeschooling. Then after I told my daughter to go back and continue her work. She turned the attention to me and why I had chosen this and was I overwhelmed etc. I showed no signs of depression or being overwhelmed at all. This was my second child, and my daughter and son are 6 years apart in age so there were no concerns present. She then **rushed through the baby check, missed the fact that my son had tongue tie**, which I then informed her about and asked her to advise me on. All of which was **rushed as she had spent most of the appointment asking about a 6 year old**.*

*A few days later, I then received a call from the LA demanding an appointment to come to my house for a visit. I asked who informed them and they said the midwife. I asked if she had raised any health concerns, they said **none at all**, I said then it's not compulsory, however **she said it was**. I said I've just had a baby and do not want to hold a meeting. She said she **will escalate and report me**. The next day her manager called me and I informed her it was not compulsory and I was only a week post-partum and was not accepting visitors. She said she would speak to her college for telling me it was compulsory to visit my home as it was **not**, and would leave me be, **for now**."*

This account helps to illustrate the chain of additional stresses and difficulties which data sharing without consent can cause for caring families.

*"On multiple occasions, with multiple healthcare professionals, consultant paediatricians, GPs, hospital doctors and nurses. It has been rare for us to have had a consultation in which we were not **questioned** about our choice. On **none of these occasions did the healthcare professional have an understanding of EHE** and it is most often the **very first thing** that is mentioned/questioned **before even thinking about the presenting condition**. On most occasions the ability of the children to interact **socially** has been brought up / with the **assumption being that they do not have the opportunity to socialise with peers**".*

*"My son has had recurring throat infections/ tonsillitis however **because his school attendance record is not relevant**, due to being home educated, I **believe they are not taking this issue nearly seriously enough** at our local GP practice.*

*"I would **never choose to avoid accessing health care** for my family. However, I **should never have to be put in the situation of weighing up the pros and cons and choosing the lesser of two evils** – debating whether to postponing access to health care for as long as was safe in order to deflect and **avoid the risk of damaging effects** of unnecessary and damaging intrusion of poorly qualified LAs into our children's education, with the inevitably negative effect LA intrusion may have on their education and on our wellbeing as a family.*

*LA input inevitably has a constraining and inhibitory effect on child-focused home education. **We should never have to be put in the position of choosing EITHER open access to health care OR ensuring our children have the most suitable education for them – we desire as home educating parents to do our duty to ensure both**".*

Examples of lack of understanding of school-trauma by HCPs

*"When seeking support and a referral for my child, my GP repeatedly told me that they **didn't approve** of home ed, saw it as a **safeguarding** concern in and of itself and told me that my child **wouldn't be depressed if they were socialising at school**. This was **despite me explaining my child was suicidal due to bullying and school associated trauma**. They made me feel like they **weren't interested in helping my child** once they heard they were home educated."*

*"**Not understanding the pressure of poor mental health which led to withdrawal from school**. And not understanding how to deal with a trans child with body dysmorphia and **serious mental health issues because of the school environment**"*

*"A lot of **pressure** from physiologist and GP **to send child to school** for mental health despite the fact **school was a big part of the decline of their mental health**. For two different children".*

Examples of HCPs expressing personal opinions to parents:

A number of respondents shared their experience of HCPs such as GPs indicating that they thought EHE is not as good as school, that school is better, that school is necessary for socialisation, or that school would be easier for parents (with parents of ND children commenting that the opposite is the case).

*“GPs have often made us feel that in their view home educating is **not as 'good'** as school.”*

*“Health Visitor **criticised decision** to home educate, saying it would be **bad** for my children, and said they **thought it should be illegal**. **Obviously, this harmed our working relationship**”.*

When such negative personal opinions were expressed or conveyed, they often appeared to be not only unsolicited and beyond the scope of the professional relationship, but also without discussion or a willingness to hear and understand the experience of the family.

*“...told me my child was **better off in school without even asking about the home education**.”*

*“Other medical staff have **expressed personal opinions** that school is necessary for socialising, particularly for neurodivergent children whereas home education better supports neurodivergent children’s’ needs better.”*

*“...Paediatrician, telling me I **have to send my child to school**, she **doesn't agree** with home educating as my daughter **will not learn or get the help she needs** and it's the **only way for her to socialise**.”*

*“Nurse at my GP **questioned me intently and pushed her beliefs of school onto me**. **Always treated me differently on subsequent visits** and will say, “Oh, you’re the home Ed mum”. Same nurse complains her son, who is at school, swears at her and is abusive, but judges my choices?!”*

Further examples of negative or discriminatory personal opinions expressed or conveyed to home educating parents include:

*“I have been **pressured** to put my children in school so they can be **‘normal’/ learn to cope (not thrive or succeed...just “cope”)** and in fact they can “get away with being normal” so should be in a “normal school”... I have been told their difficulties are my essentially **my fault** (they are neurodivergent) despite trying school and it made everything worse. ... I've now moved county and am **relieved I won't have to deal** with them again.*

*“HV was **pushing** sending toddler to nursery, ended up **pulling both children off the HV service as I was so anxious about being judged or questioned**”.*

*“On Consultant letters (more than once) Home Education was **listed under the heading of problems** and I had to contact the hospital and **request a correction**... did not stop the consultants from **still believing it was a problem, even after I explained that it was the only reason my child had not chosen to end their own life**”.*

*“‘Homeschooling’ was listed under **list of ‘problems’** in clinic letters by a senior community paediatrician, even though he appeared relatively favourable in relation to home ed. I should have challenged this, but didn't as **didn't want to “rock the boat” or precipitate any negative reactions that could have made accessing health care more difficult**. I should have challenged it because he was a very senior and influential doctor, so even if listing “homeschooling” as a “problem” was a mistake, if other clinicians saw this and thought it was his opinion then it could have **an adverse effect on their perceptions both of us and of home education in general**. It also would seem to reveal **at least some degree of unconscious bias**”.*

*“Upon hearing my son was home educated a consultant voiced that all kids **need school** and friends and **being bullied builds character**.”*

*“The majority of interactions I have had with health care professionals have been negative in regard to ‘homeschooling’, ranging from a doctor telling me how **sorry she felt for home educated children as***

*they are so isolated and don't get school trips. Then there are the receptionists/nurses/health visitors who are **hugely misinformed** some comments I've had are "is that even legal?" "You're setting them up to fail" "But you aren't a teacher how on earth are you going to teach?" "But he won't be able to do his GCSEs!" (He was 6). I could go on."*

*"A nurse made **negative** comments about home education while he took a blood sample from me, in response to me saying that I home educate".*

*"On having an operation on bones in feet, post op appointment a doctor asked about schooling, then **went on for almost half hour how home educated children fail in life**, giving examples of how his own children had achieved great things in school system. On follow-up visits **strongly continually expressed his opinion** (that was) **not relevant to the care** or treatment given."*

*"CYPS nurse stating **children needed to be in school to socialise and that they would have no future prospects without a school education**".*

*Parent of a child with ASD and sensory processing dysfunction reported how a dentist was "**not positive about home ed, treated me as being negligent** of son's teeth after I was unable to get near them on one side due to a wobbly tooth, which I explained at least 3 times..."*

*"My child has some complex congenital health needs and is seen by various consultants at a major children's hospital. Both her main consultants have **queried repeatedly** why she is home educated and **expressed their personal disapproval of home education**. One **queried its legality** in the UK. I'm aware that HE is likely flagged as a potential safeguarding red flag during **training** of all staff at this hospital and am **profoundly uncomfortable about having to see consultants there**. On **every visit admin staff ask what school my child attends for their records**, despite home ed having been stated frequently, and there's often an **eye roll and sigh in response to the answer 'home educated'**."*

*"When attended A&E for my daughter's fractured elbow, the receptionist's only question was what school she went to, and I replied with the last one she was in. She **smirked, obnoxiously** handing me my **case sheet that stated 'not in education'** on it. It is my opinion that the receptionist was **unprofessional and judgmental**."*

*"Do you have the **permission to home educate?**', 'what do you do that for?', 'you should follow the national curriculum or **they won't get into college or get a job**', '**you and your children need to be monitored due to home educating**', 'you must let the lea meet your children so they **know they are safe**', '**surely your children are missing out socially?**'"*

*"Comments about home education **not being sufficient to get a good job, i.e. doctor**."*

*"I'm actually a student nurse alongside home educating and often have comments from HCAs asking when my child's going back to school upon learning they are home educated and asking **how she's going to get a job when she's older**. I also was home Ed (and) made it to uni. Nurses have yet to mention anything, but I believe health care workers should be advised that home education is not a safeguarding concern. **There are things to look out for and that is not one**".*

Examples of home educated children being directly exposed by HCPs to expressions of negative personal opinions or discriminatory attitudes:

*"...quiz my child on "what you've been studying today" – in a way that **would not do to school children**".*

*“Tested the child's academic skills in a way that would not happen if child was in school. Asked child direct questions **about if they were happy at home** in a way that wouldn't have happened had they been in school. When child has been in school none of the above occurred. This is **discrimination**”.*

*“The Optician's Practice Manager was **angry and disparaging** that she had an appointment during the school day and **kept shaking her head whenever our daughter spoke**. (The Optician who did her eye examination however, made a point of telling us how clever she is, how she asked intelligent questions about the process etc.) We are **very reluctant and nervous** about her follow-up appointment as a result as we were **very uncomfortable**.”*

“Repeatedly asking why child wasn't in school, wouldn't they prefer to be in school.”

*“GP know that my 8-year-old is home ed but **repeatedly ask him about school**. He gets **understandably frustrated** about having to explain why he's not at school **when he's there for healthcare not to be quizzed about his education**.”*

*“GP **distracted from the actual health problems at hand**, interested instead in **quizzing me on my academic knowledge** (specifically, asking me at age 14 about times tables and inviting me to spell words, which was **pretty insulting** as I already had GCSEs by then).”*

*“Psychologist who **pressured older child** to go to college despite them having said they wanted to be home educated”.*

*“I was aware that one GP **didn't agree with our decision** to home educate and they then went on to **ask probing questions** when I volunteered that we home educated making both my child and I **feel quite uncomfortable**”.*

*“My **children became cautious** of visiting the GP because **they felt they would be asked awkward questions about friends and socialisation as had happened before**”.*

*“My child was aware that **they felt judged** for attending appointments with me, their parent, but they wanted me to be there”.*

*“Both children felt a good relationship with parents was **held in disbelief** and that as a home Ed parent, I was **treated suspiciously** and that as a home educated child they were **asked unnecessary / unrelated questions**”.*

*“Although...our surgery is supportive of HE, we did have one difficult, negative experience with a locum doctor...Initially, the locum was welcoming and friendly, until she learned that we home educated. She then spent the majority of our appointment questioning our education choices and **asking our son intrusive questions**, such as whether he could add or subtract or even if he knew his timetables, none of which had any bearing on the subject of (his health issues). Our son answered her politely, whilst I informed her that his education was not the subject of our appointment, but **she gave us a lot of grief**. She then did make a referral to the physio department for him, but in a **condescending and reluctant manner**. Our son said afterwards that the **doctor made him feel uncomfortable and somehow illegitimate, something he had never experienced at the surgery before**. Thankfully, we never had to deal with her again, but it **helped us to consider how to take control of conversations in clinical settings in the future**. We **considered making a complaint**, but as she was a short-term locum, we felt that there wasn't much point in doing so”.*

*“The attitude of several different nursing staff or nurse practitioners has started off expressing interest and then **developed into interrogation** of how I am a home educating parent is scrutinised and checked up on. This had led at times **questioning of my son** as to whether it's what he wants to do and then asking about exams and career paths.*

It makes us feel very uncomfortable and not want to have face to face conversations with nurses.”

Examples of damage caused by negative or discriminatory attitudes of HCPs on practitioner-patient relationships with EHE families

*“The outcomes will **not improve the ability to check on children at risk**, we are now ...**less open with medical professionals and has definitely broken down the relationship, so now if they ask anything they get one-word answers**”.*

*“For us it's mostly been a general ignorance about HE but, for the most part, the medical staff we've seen have been **polite and asked questions rather than confrontational**. We've not needed much contact with medical staff beyond vaccinations so haven't had many interactions. Our friend has had more difficult interactions with A&E staff implying HE was **irresponsible & should be illegal** & that their child **could be at risk**. My friend is a fantastic parent & a very competent educator...*

*Knowing that my friend has had experiences like this does **make me nervous** about interacting with medical staff. It occurs to me every time I consider seeking medical advice for myself or my children that someone **might report us as a safeguarding concern purely based on our HE status**. I wouldn't let this **anxiety stop me** from seeking medical care for my children if they needed it, but it does make the experience **more stressful than it already is**. I once spent several hours in A&E **anxiously rehearsing answers to any questions** I might be asked about HE when I would have liked to have been able to just focus on my child.”*

*“**Fearful to schedule appointments during school day because of the resultant interrogation about why my children aren't in school**. Also, **generally anxious** about any appointments or interactions with health care professionals which involve the children”.*

*“I **avoided my local hospital's A&E** as I had heard reports that they had previously **reported a number of Home Educators to the LA**. I was thankful that I could attend a **different hospital's A&E** instead; one that I knew didn't do this. NHS data sharing with interfering bodies (such as the LA), **will produce more harm than good**...People need to be **confident that their data remains private and only with the healthcare they are accessing**. **This is the safest outcome for any child**”.*

Responses to question 5b,

This question gave the opportunity for respondents who had put in complaints or voiced concerns in relation to interactions with HCPs to comment further, in addition to comments already given on this topic to answer 3g.

Responses in this section included:

*“I raised a concern on health professionals overstepping boundaries. Was told that if my health was a concern that all options should be considered. I did ask if every parent was asked about the education of their child/ren but **never got a satisfactory answer to that**”.*

*“It's just really off-putting and concerning to have these experiences and makes me **hate visiting health care practitioners**”.*

*“I **wouldn't complain for the fear of what would happen**”.*

*“I just felt extremely upset and angry the way this was done and it makes me **feel upset seeing health care professionals for my family**.”*

“Did not complain for fear of not being able to get my family the care they need in the future. There are no other GP practices who will take us in due to area boundaries”.

*“During the complaint, I found the medical professional checked with the local authority on the law and what they were supposed to do, the LA guided the medical professional that they had acted as the law states, **(they had not, it was not about a SG concern)**”.*

“I believe the GP passed our information to the Local Authority based on a comment by the LA EHE person insinuating it is common practice for GPs to pass on information once they know a family is home educating”.

*“We received a meeting with professionals that already knew us and aware of us home educating, so that part was fine. However, we really needed the resources of CAMHS and **lost all trust**. As did our eldest child. Absolutely disgraceful behaviour - especially when there is **such little help for mental health**”.*

“A club my son attended, made a social services referral, completely in error, by their admission, because of poorly trained staff. They didn't follow their own safeguarding policy or national guidelines. It triggered a MARF. Social services dismissed the reporting by the club and called it ridiculous. However, the MARF triggered an unannounced home visit by local EHE Advisor, even though we asked for all comms in writing. So, we are now on multiple agencies radar, no doubt including health professionals, because of an error, even though social services have dismissed the case.”

“Made a complaint about a nurse to the GP surgery where they worked. I was told the nurse was correct and following protocol to report home education as a safeguarding concern. It's part of their safeguarding training.”

Note to clarify again that the information given in any such training session would have been incorrect. Home education is a lawful choice and is not a safeguarding concern.

“Would not allow access to ASD or ADHD assessment as Home ED and a girl because it's only boys who have it and her PTSD from school, would go if she went back to school”.

“Was more a case of educating the provider as they did accept my explanation, but we were initially refused NHS funding because my daughter was home educated and being ‘home schooled’ was [incorrectly deemed] not full-time education.”

“I'm complaining to NHS about a consultant at the moment that took me into a room alone made it clear that my son should be in a school even when I said he's home ed and Sen and trying to get EHCP / EOTAS. She was very bullying. She put a safeguarding referral in same day that's now been closed as it isn't a safeguarding issue.”

Note to clarify for the reader, EOTAS refers to education that is provided by the LA rather than the parent for children who are unable to attend school for a variety of reasons. This respondent was trying to get the authorities to help their child in applying to get this and an EHCP. Such applications can be very challenging and time-consuming for parents, especially outside of the school environment, demonstrating the extent of care and input this parent was investing in their child's education.

“I wrote a letter to the doctor involved, detailing my frustration at her ongoing criticism of home education, when it wasn't her place. I believe she referred us to “Early Help” however they met us once very briefly and that was all. We were then changed to a different paediatrician, who was fine.”

*"I had contact from my LA saying they had been made aware that I had moved house and that they wanted to pass on our information to the other authority. They had my full new address. I had just lost my father and we were in the process of moving. I would have liked to pass my information in my own time. We were not due a yearly review and it caused unnecessary stress. I had to ask where she got the information as I had not changed the GP yet. However, we had had a trip to A&E following an accident at a forest school my son had been attending locally while we were down caring for my father before he died. As a result of the information being shared, I **felt extremely uncomfortable. I care for my child as is evident in my taking him for the care he required.** It was surprising to then be immediately followed up (in terms of his education regarding changing LA). Not only that, the currently LA had information for the child at the hospital but took it upon herself to pass on the details of my 2 other children. I had every intention of contacting the new LA once we had laid my father to rest and we had fully settled in our new home."*

*"I was reported to social services who visited our home unannounced, but they were very respectful and apologised citing Home Education was the reason for visit, although they knew that wasn't grounds for a visit. They promised me a report stating they were very happy and thought my children were thriving. I never received a letter from them. My **eldest daughter was heavily impacted by this and will avoid GP/Hospital appointments now as a young adult.**"*

3.2 Responses to question 5d:

Additional comments regarding why respondents chose not to make a complaint or voice concerns despite believing they had grounds to do so (beyond responses given to question 3g):

*"**Fear of being discriminated against due to disability**".*

*"From past experiences, **complaining didn't work. I wasn't heard**".*

*"We would not complain again, as during the complaint I have been told, **'Well if you aren't doing anything wrong what's the issues, it doesn't matter if we share the data'**."*

*"The idea that a parent could be fighting them not following the law seemed to go straight over their head, there was an **obvious disregard for anyone's private life**."*

*"I am Autistic, and the **'fight'** was simply too much to process at the time as we had just moved to the area/ had no internet/ stuff in boxes, etc and the idea of [the potential risk of] a malicious referral to Social Services was too much. They clearly have no issue passing information around and I couldn't risk my kids' safety/ wellbeing in a new place, let alone my own.*

"I did not feel I would be listened to; I wasn't".

*"Feel they have too much authority over us and our children, that **complaining would put us at risk for further malicious reports**."*

*"I have ADHD myself and have suffered with mental health issues and worried that because of this, I might not be seen in a good light. I might be looked at as the problem. **Worried about being***

accused of FII as that was once implied by a Paediatrician who asked me why I was so determined to have my child assessed for Autism and PDA as if I was pushing something that wasn't there. Also, my own health issues make it **difficult** for me to find the time, energy, mental capacity to do something like make a complaint.”

“It wouldn't have changed the thing I cared about, which was not having my child's details passed on. If a complaint could have resulted in my referral being deleted, I would have tried.”

“I haven't needed to complain because as far as I am aware my information hasn't been shared. I definitely would complain if it had.”

“I didn't think it would make a difference”.

*“I voiced my dismay to other professionals I could trust but not to two of the ones connected to the school. Two were fine ... but the other two seemed totally directed by the school. **No way I could raise any concerns about them. I felt I'd be gaslighting and turned on.** I just wanted my child to be safe, mentally, emotionally and with us who understood him best.”*

*“My concern would be **highlighting ourselves again in the minds of consultants on whose ongoing medical care we are reliant.** I'm fairly certain that the hospital flagged us to our LA when my child turned 5 (CSA) but no proof.”*

*“There would perhaps be times when I wouldn't complain because of the **stress and aggravation that it would cause...**”*

*“I felt unable to complain about the nurse as she would have obviously **known it was me and I will need to see her again in the future.**”*

3.3 Responses to Question 6:

Question 6 gave opportunity for further comment on the impact on home educating families of non-consensual sharing of their data by health care services.

Responses included:

“It will destroy all trust”.

*“We are legally allowed to choose home education: in our case and for many others we know it is an indescribable improvement on school for a wide variety of reasons. The constant **attempts to chip away at or undermine this right (including sharing of data inappropriately) is destructive, decreases confidence** and sometimes leads people to actively avoid contact with anyone in authority in any system which is **self-defeating.**”*

“It creates the assumption that home educating families are guilty of potential harm to their children when home education is not only legal but often the only safe choice

*for many families. A policy being in place that expects all data to be shared simply for the family having at least one child home educated conveys a message that the family are doing something wrong when there is no evidence nor reason to believe such a thing. The fact this is only targeted at home education families and not families that have children in the school system makes it very clear this is **discriminatory** toward home educating families and has nothing to do with children's safety at all."*

*"By implementing a register where all home educated children must be legally on roll **gives the impression that home educators can't be trusted** & will **massively damage any relationships many home educators have with health care professionals & the LA.** It could even put some home educators off **accessing services** which would be **extremely detrimental** to their children."*

*"It **implies that elective home education is a safeguarding concern which it is not.** There is no way that a healthcare professional can know whether a child is receiving a suitable education based on their assessment (which is likely to be clinical and not educational) so how is it helpful for them to report us? A referral from a clinical professional to the LA would likely get the relationship between LA and home educator off to a very bad start."*

*"Shortly after attending the dentist for a routine checkup, I was contacted by the LA who had not reached out for the previous 3 years. This gives me reason to believe our **data was shared**".*

*"A friend expressed trepidation about visiting the dentist ...because they were concerned the dentist would assume they were being neglectful because they are home educators and refer them to social services. Thankfully we attend the same dentist, and I was able to reassure them that wouldn't happen, but I think **fewer families would attend dentists if their data could be passed on as a matter of course.**"*

*"Health care data should be **completely confidential** and not something governments can use to create unnecessary databases that can be mishandled. If there are clear concerns about a child, there are already processes in place to flag these up, so there is no need to break patient confidentiality to do this. Patients, including children, **should feel protected when seeking out healthcare,** and using health care data for government databases is not protecting patients. It is government interference."*

*"How people who EHE are perceived can be quite negative. The **negativity from professionals can stop people accessing the resources they need.** Everyone needs to be more educated about what EHE is and how it's not bad, just different. This needs to be training in all places."*

*"Home education is often **misunderstood,** and health care providers are overly and **needlessly intrusive.** We **drove more than 750 miles on 7 separate occasions to get essential Covid vaccinations and flu nasal vaccines** for her. Our GP does not support home education at all and **when she mentioned she was being bullied at school he responded with, 'No you are not.'**"*

*"I believe making the sharing of our data legal could and probably would have a massive effect on whether or not people go to health care services when needed. **People won't seek help from people that they don't trust....** **Health care should be just that.** Health care professionals should focus on their role and are not experts in education and this ruins the medical professional's relationship with the patient"*

“Home educated children have the same rights to confidentiality as everyone else. The method of their education should not affect how they are treated by health services.”

*“Our medical data is supposed to be confidential. I signed an online document a couple of years ago to say my GP does not have consent to share it with other organisations, but they still have. **This massively reduces my trust in them. I now wouldn't trust them not to contact the LA, who so far have no knowledge of us.**”*

*“I know of a few families where the health visitor has told the LA the family are home educating. **This damages trust and relationships with both health care and the LA.**”*

*“We choose legal and lawful default option when it comes to our children's education. If our children are being seen by healthcare professionals and there are no concerns raised about ability to parent, then there should be zero reason to inform the LA of our educational decisions. **The thought that if I take my child to see a HC professional, I would be reported to the LA, would definitely give me pause for concern and I may second guess the need for that HC visit.** Many families have managed for years without LA involvement and their children are thriving, the thought that that could be turned on its head due to overzealous LA involvement, could lead to many families holding off on medical treatment. Weighing up the risk of whatever the medical issue was, with the thought of LA involvement, would for me **raise the bar needed for me to seek medical help.**”*

“I do not see why some people in this country would lose their rights of confidentiality, GDPR, private life just because of the way they have legally chosen to educate their children?”

*“Why would they have **less rights** because of it?”*

“The move for total control is merely to oppress and for excuses as government are embarrassed by the mass exodus of parents who rebuke public education offerings as they are inadequate”.

*“I think it is **dangerous**. Families are **afraid to seek** help and approach health care professionals in times when it is needed for fear of having data shared and being **put under the microscope** for their choice to home educate their child.”*

*“The impact on data sharing could have a larger negative impact on the home educating community because parents would feel **reluctant to reach out to the health professionals if they felt that in some way it would cause significant harm or upset for the child and their families.** Therefore, that would have the complete opposite end goal and not **safeguard vulnerable children...** Time and time again we as home educating families **feel threatened, misunderstood and judged.** Look at the statistics of how well children that are home educated do in comparison to school children, I think then the government would be pleasantly surprised and stop this witch hunt.”*

*“I feel non-consensual data sharing of home educating families **legitimises and perpetuates the unfounded stereotype that home educated children are automatically at risk of harm.** If we green light that kind of data sharing, we are **further embedding that idea**”.*

“I don't have stats, but I'd wager to say a huge percent of home educated kids are so because they're disabled. If we begin routinely, and unjustly sharing data about these children we are verging on discriminatory behaviour. Focus needs to be on supporting families who ask for help - but this is less

likely to happen when home educated families are treated as automatically neglectful or harmful and have to then prove they are not.”

“V concerned that **LA data is not secure... Way too open to abuse.**”

“I fully understand sharing data if there are genuine safeguarding concerns, but I believe sharing without safeguarding concerns, without consent, **deeply undermines trust.**”

“I now **do not mention education at all** in front of medical staff, and get most of my healthcare privately under a **pseudonym**, so I **don't have to worry about discrimination**. It is far from ideal, but I would **rather have privacy than keep my records in one place or save money.**”

“I think it will **discourage some families from making full use of health services**. They will **think twice** about whether they need to access that service, because it may have negative consequences for them, i.e. data being shared.”

“I feel that if health care professionals are told that they have to report all home educated children, they will **view all home educated children as children at risk of harm**. **Parents bringing their children to health care services do so because they care about their health and well-being**. For the few children that seem as though they may have suffered abuse, there is already a system in place to help them.”

“I believe it is harmful to **automatically treat all home educating parents as a safeguarding risk** to their children. It is a form of **bigotry.**”

“Health professionals need **educating** on home educating families and keep professional by **not judging or having a personal opinion** in topics that are not safeguarding concerns”.

“**Data sharing without warrant assumes families are already guilty of something before any evidence has been presented**. Home educating families have a right to privacy which should not be violated because of our educational choices. This would **undermine trust in health care services** and leave **perfectly good home educating families vulnerable** to health care professionals with an axe to grind that might like to ‘catch them out.’”

“I expect my relationship and interactions with my health care professionals to be confidential. Sharing of my information would be a **violation** of what I believe to be a rightfully confidential situation.”

“I would be **afraid** of accessing health services if I thought they'd have a problem with HE. I already have the protective attitude not to take my child to GP unless necessary because of the **risk of intrusion** by the LA should the GP notify them due to **prejudice.**”

“It will **put families off getting health care** because they want to **remain private and enjoy home education.**”

“I have been a teacher for many years and seen the positive impacts that information sharing between difference agencies can have on certain situations and the lives of young people. However, I have also seen the **destructive power misinformation, bias, prejudice, slander and harassment of**

parents and families. I believe that there are some cases where intervention can be key however I strongly believe that this is more achievable (and therefore making it more approachable for HE families) that it is **relational based**. Trust in the government and local authority is **built on full transparency and consent**. Creating a scenario where personal information is shared without consent breaks down a relationship of trust with a healthcare provider, and with the local authority.”

“We are **less likely to access** vaccination services where we have to declare our children are home educated as I believe this service has previously shared our data with the local authority without our knowledge or consent.”

“There is **already a mechanism for healthcare professionals to raise concerns** (and from previous research it is shown that home educated children are twice as likely to be referred, but not twice as likely for those referrals to be progressed once investigated). There is no evidence to suggest this needs to happen. It will only lead to **further harm caused by prejudice and bias** against home educators which is clearly still heavily present in the wider community. It has been shown time and again that home education is not a safeguarding concern, it is even in law, so therefore it should not be assumed, and home educators treated as **guilty till proven innocent**. Furthermore, it will **negatively impact the trust** between home educators and healthcare professionals. this trust is **vital for relationships not to break down which could lead to further harm**. When did we stop trusting each other and especially parents? When did we start to not respect the right to privacy? **Invest the time and resources in improving social services instead**. Also educate all children and healthcare services on the truth and reality of home education - not just repeat the same sentence, without any deeper information, which seems to be repeated by politicians and media such as "parents have the right to home educate and many do a great job, but.." This is not supportive and does not reflect the truth of home education in this country which many should be proud of. It feels empty and almost just placating rather than truly believing and honouring a very valid and important educational route and option for many children.”

“The government considered it wrong **to share data obtained by the NHS from illegal asylum seekers because this was likely to stop them seeking the medical help they needed**. How can it consider it appropriate to share data without consent of law-abiding citizens purely to ensure that it can identify parents who exercise their right to home educate their child? If it was likely to prevent the former seeking medical help, then surely the latter who are not breaking any law in fulfilling their duty. This reveals the **surveillance mentality** of the state and the underlying lack of respect that government have for home education. A **further nail in the coffin of good state and parent relationship**.

“A life choice shouldn't mean that you are suddenly subjected to policies that override basic rights such as the right to a private family life. **A choice doesn't equal a concern**. The existing law where data can be shared if there are genuine concerns is all that ever needs to apply.”

“I believe home educating families have the best interests of their children at heart and **would of course continue to access health care facilities as needed by their children**. However, non-consensual data sharing which may lead to LA enquiries would introduce **undue stress** into the family lives of home educating parents and their children, and also impact on the UN rights of those children and their protected homes and childhoods.”

“a former receptionist at an orthodontistwas **told to report any home ed patients to the local authorities**.”

“I strongly object.”

*"I think passing on our children's data without our consent would **prove that there is a suspicious view the government have towards us**; concerning relationships between parents and their OWN children. I think that would negatively impact many families trust in the local government."*

*"Absolutely do not agree with data sharing. I think it's **too risky for vulnerable families.**"*

*"It causes **extra stress** and leads to **children not trusting health services.**"*

*"For me anything (unless a real safeguarding concern such as sexual, physical, mental, emotional, etc abuse) needs to be kept confidential. The **LA does NOT need to know my child's [information]** unless I and the child feel necessary to share as impacts their education in some way. My child's education is mine and my child's to manage as school was not fit for purpose and did not meet needs (**thus LA failed us already.**)"*

*"Home educated children should **NOT be refused medical assessments and diagnosis simply because home educated**, otherwise what's next? Refusal because religion, colour, sexual orientation?"*

*"People **need to feel secure** that medical information will **only be shared in case of emergency.**"*

*"Every individual has the **right to protect their own personal data**".*

"Even though I haven't experienced non-consensual data sharing, I am still anxious about using health services as I don't want to have to explain why my child can't tell them which school subject they like best. It's not the place to be explaining or justifying our approach to HE."

*"One of the reasons I have completed this is due to two friends having their data shared by ***** without their knowledge or consent. This occurred despite their being no safeguarding concerns. It honestly **makes people feel less inclined to seek medical treatment....**"*

*"I feel that this idea of sharing without consent **goes against the rights of the individual and opens the door to medical professionals being encouraged to view home education as something bad that needs to be reported.** Going forward, I feel that **informed consent is the only way** and it should be coupled with a requirement that all medical professional are **educated** on how beneficial home education can be."*

*"It is a **breach of the family's human rights**".*

*"I am aware that the health system needs to know that we're home educated so that they can facilitate vaccinations that usually go through the school system. However, I don't think that the usual E consult form to access day to day health care needs to know what school my child is attending or none. **I can't see how that information is relevant to my son needing treatment for a common illness.** Nowhere on the E consult is there opportunity to express GDPR permissions or to **withdraw permissions to share data.** This is of great concern to me. I feel the breach in confidentiality makes us feel **unsafe and unvalued** as a home educating family. It also leaves us with status of being **subpar** to other families, which I believe **does not promote equality.**"*

*"I accessed A&E with my middle daughter and assumed we would have our data shared purely for home educating (we are under the radar) but weren't. The fact that the **thought** went through my head and gave me pause for thought is bad enough. **I shouldn't have to make a choice between health care access and privacy.**"*

*"I am **petrified** of even telling a health care professional that I home educate as know lots of home educating families who have been **demonised** by health care professionals. I am **scared** accessing health care for **fear** of my daughter being forced to attend school for no good reason."*

*"The **assumption is made that something wrong must be going on in home educating families so they must be checked up on.** They have a right to privacy so data must not be shared without their consent."*

*"This is likely going to have an **extremely negative impact** on the home educating community should it be approved. It will cause many families **not to trust medical professionals and/or possibly disengage with them...** This of course would **impact both parent, child and the health professionals involved.** It is therefore in the best interests of all involved for GDPR, parents rights and parental consent to data sharing to remain. It is best that it is kept as it currently is meaning allowing parental consent on data sharing to be sought and not overrule parents by removing their rights of consent to sharing of their children's details as this will **foster a relationship of distrust between both parties.** It will not foster the positive and engaging relationship that Local Authorities/Health bodies are looking to form with the home education community if they go ahead with **removing parental consent to their children's data being shared without their consent.**"*

*"A good friend of mine had her **details shared** by her son's speech therapist with the LEA **without her knowledge.** Unacceptable."*

*"This will **put some families off accessing health services and some will pay for private GPs.**"*

*"Home educating families will feel **more reluctant to access healthcare early and less confident in their relationships with healthcare providers** if nonconsensual data sharing is required. Health care data should be **confidential...** all families should have the right to privacy."*

3.4 Responses to Question 7:

Further comments regarding what respondents felt could be done to prevent the kinds of situations addressed in this survey included:

*"I think all education of health care staff should be developed (and preferably run) **by those who actually know what they're talking about** (home educators or people who advocate for / champion them)."*

*"If there was a **consistent non-hostile approach by the LA** towards Home Ed families then being known to them wouldn't be a problem. **But until** that is the case we would rather not be known."*

*"Simply for health care professionals to **not to consider that they have the right to force their personal opinion on any patients** about their views on home education and to not overstep their remit. Education is not their responsibility or concern."*

*“There is a system narrative that implies home educated children are more at risk than school children. **The figures prove this wrong.** There is also encouragement in the media to believe home education is detrimental and a safeguarding risk. This is **systemic discrimination.** All professionals who work with children should be informed of actual data that shows home educated children are often the least abused and the best taken care of by their families. They should also not be allowed to question families or children about this matter. In our experience one of our children was severely questioned as though they were at risk. Another time with another child who was in school at the time the child stated himself that his school were abusing him. The health care staff laughed!! He was being serious. So, ... not only do they need to **stop discriminating against home educating families but the children's system needs to take abuse claims from children about their school seriously.** At least as seriously as they would if the child said their parents were abusing them... Also statistically children now are at more risk at school. As schools have become incredibly dangerous places. But no one talks about that...”*

*“The overall understanding that **parents have a right to parent, not the State.** Laissez-faire.”*

*“**Government and health care staff** need to understand that **people who don't trust them won't go to them for help.** This would be very dangerous for many. We all need to feel that we can ask for medical help without worrying about the consequences that may come with that request.”*

*“We should be given a **consent form** - everybody - **to opt in** to data sharing if we're happy about it. It should **not be mandatory at all, it's against our human right to medical privacy.**”*

*“The **inherent bias against home education** is prolific and endorsed time and again by the media...”*

*“Another way to prevent many families from turning to home education is to **listen to families.** Many children have probably tried school at some point and were removed. The question from the government should be **WHY?** Make huge changes to the out-of-date school institutions. Make them smaller, friendlier, inviting places with a real up to date educational experience. Look at other countries and what works well and implement positive changes instead of blaming everyone else for the failure of the school system.”*

*“More **research,** and more widely available research, on home education and the outcomes of children who are home educated. Of the few studies done, home educated comes out as a “better” option for children than mainstream - e.g. on happiness markers, academic success and future employability. But this research is hard to come by for those interested in the subject let alone those with only a suspicious stand point.”*

*“**Right to have data deleted if it has been shared unlawfully.**”*

*“**Independent experts that advocate** for home education ... (on) a very large board that advises and educates health care staff, as well as the entirety of the government.”*

*“I feel that medical staff should have to do a **basic safeguarding module, and accurate legal info about HE** should be included. It should be a compulsory module.”*

*“Better understanding amongst health care professionals regarding **confidentiality policies** of their clients/patients' information with particular reference to home education. Also, better governmental understanding of health care professionals code of conduct with regards to confidentiality. ”*

*“I think we need greater clarity about **GDPR** and other relevant **data protection laws,** and whether we can assert that they are in fact breaking the law by sharing or enlighten the home ed community that these laws don't in fact protect us.”*

*“I understand a health care practitioner needing to report suspected abuse or neglect of a child. However most home educators are decent people doing their best for their children and overall their **privacy and autonomy needs to be respected.** **Work with home educators** is one of the best solutions and ways forward.”*

*“Healthcare must legally tell parents if they are going to tell LA re home education. At the moment data seems to be passed about behind our backs without consent or informing us. It just leads to a **culture of mistrust and suspicion which is ultimately negative to everyone**”.*

*“Health care professionals need to be told that the **education of a child is not within their remit to question or comment on, just as they wouldn't question or comment on schooled children.** MPs and Peers should not be allowed to make negative allegations, specifically statistics about home education or their parents without providing the **evidence** for independent scrutiny”.*

*“Statutory guidance and advice from Government to Local Authorities which clearly outlines the legal rights of home educating families, and mentions that if a referral is received by a LA from a healthcare provider which is simply because a family is home educating (and there are no real concerns) then the **LA must take no action to investigate the family and must write to the healthcare provider concerned** to explain no action will be taken and their referral was unnecessary and they should not refer for such reasons in future”.*

*“It is **not safe** to tell health-care professionals we are home educators...”*

*“For all health professionals to be properly informed that **Home Education is not a safeguarding concern** or to be led to think that if they encounter a home educating family that they have to report them”.*

*“For health professionals to receive training so that they **do not treat home educators with suspicion** and so they do not question them about the Home education provided and/or question them on it when turning up to appointments.”*

*“Doctor's educational modules regarding safeguarding should explicitly teach that (home education) is **not a safeguarding issue** in itself. At present, I know some of their leads do assume there is some inherent danger, in ignorance of the statistics”.*

Appendix A: Survey questions used in this study.

Confidentiality Breaches and Data Sharing about Home Educating Families without Consent - from Health Care Sources to Local Authorities.

This survey is conducted by HEACH – Home Educators Advocating for Confidential Healthcare - a group of home educators in the UK concerned with preserving confidential access to health care.

It has been the experience of some home educators throughout the UK that their children's data has been wrongly shared by health care sources with local authorities, without their consent, purely because families have chosen the lawful option of home education (and in the absence of specific and legitimate concerns).

Furthermore, there have been considerations and proposals that health care services should be required by law to share identifying data on ALL children with local authorities without parental consent so that local authorities can then make formal enquiries about the educational provision for all children who are not on a school roll (this is undergoing a consultation phase in Wales at present).

Information can ALREADY be shared if a health care service believes that a child may be at risk of significant harm (i.e. safeguarding concerns), and this would not change.

The questions here are regarding routinely or automatically sharing data where there is no reason to believe that a child is being harmed. This may include occasions when home education is falsely considered to be a safeguarding issue in and of itself, when non-home educators do not understand the legalities of home education, or when non-home educators mistakenly conflate home education with school-based outcomes or approaches.

This survey seeks to identify the potential impact of non-consensual data sharing by health care services with local authorities, based on the experiences and opinions of home educators.

The collected analysis of this survey will be conveyed to governments, authorities, and professional bodies that represent clinicians. It will also be accessible to home educators. As collated analysis of this data will therefore be likely to be accessible in the public domain, this survey is anonymous to protect confidentiality and respect privacy.

For the purposes of this survey, the term "health care services" is used to include health care professionals, health care sources or departments, NHS trusts, and - in Wales - local health boards.

Please tick this box to confirm you consent to your response being included in the anonymised analysis of the data.

(1a) Additional info

(home educating parent/carer includes any adult responsible for home educating a child).

If you are a second-generation home educator, please select the first two options.

- I am, or have been, a home educating parent/carer
- I am, or have been, a home educated young person

If you have answered "Other" to that question, please briefly explain below your interest in these issues and reasons for responding.

Please choose and note down a 'codeword' that you can use to request removal of your data should you change your mind.

This is optional.

Please email heach2024@gmail.com if you require your data to be removed.

(1b) Please indicate where in the UK you are based.

If you presently live in one area of the UK but are relating to experiences in another area, please tick each box that applies.

- England
- Wales
- Scotland
- Northern Ireland
- Other

(2a) Do you agree that health care services and providers should share data about home educating children with local authorities, without fully informed explicit consent of parent or child, solely because the child is being home educated?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

(2b) Do you agree that health care services should be required by law to routinely share data about ALL children with local authorities, without fully informed and explicit consent of the child or parent, for the purposes of the LA developing a list/database of children not on the school roll and making formal enquiries about their education?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

(3a) Have you been in a situation where:

- a health care services member of staff has given you false or mistaken information about home education?

(There will be opportunity in a later question to comment further on this, if wish to.)

- Yes
- No

(3b) Have you been in a situation where:

- a health care services member of staff has demonstrated a lack of understanding of home education, either regarding the legalities or the day-to-day practicalities and approaches?

(There will be opportunity in a later question to comment further on this, if wish to.)

- Yes
- No

(3c) Have you been in a situation where:

**- you felt pressurised by a health care services member of staff to not home educate your child, or to send them to school,
- or where you felt that they considered home education to be a less valid approach to education than school-based education?**

(There will be opportunity in a later question to comment further on this, if wish to.)

- Yes
- No

(3d) Have you been in a situation where:

- lack of understanding or awareness of any aspects of home education by any form of health care staff affected your family's relationship with clinicians or health care services?

(There will be opportunity in a later question to comment further on this, if wish to.)

- Yes
- No

(3e) Have you been in a situation where:

- the approach to or understanding of home education by a health care services member of staff has affected the clinical care your family were able to access?

(There will be opportunity in a subsequent question to comment further on this, if wish to.)

- Yes
- No

(3f) if you answered yes to these previous questions, which type of staff member was this?

i.e., which type of staff member(s) either:

- conveyed false and mistaken information about home education,
- and/or demonstrated a lack of understanding of home education, either regarding the legalities or the day-to-day practicalities and approaches
- or where lack of understanding or awareness of any aspects of home education by any form of health care staff affected your family's relationship with some form of health care provision
- or where you felt pressurised by a health care services member of staff to not home educate your child, or to send them to school
- or where you felt that they considered home education to be a less valid approach to education than school-based education?
- or where this affected the clinical care your family were able to access.

Please tick all that apply:

- Hospital doctor
- GP
- Nurse
- Midwife
- Health visitor
- Dentist
- Optician
- Paramedic

- Occupational therapist
- Physiotherapist
- Speech and language therapist
- Psychologist or psychotherapist
- Admin clerk or receptionist
- Other

(3g) Please share more information below about your experiences if have answered yes to any of the preceding questions.

That is, please share your experiences of any:

- misleading or false information you were given by a health care member of staff
- comments/indications that they did not understand either the legal aspect or everyday practicalities of/approaches to home education,
- impact on your relationship with a clinician or department, including in being able to maintain a trusting relationship,
- situation where you felt pressurised by a health care services member of staff to not home educate your child, or to send them to school
- situation where you felt that they considered home education to be a less valid approach to education than school-based education?
- impact on health care provided.
- other relevant comments.

This information can be very useful in anonymously conveying the experience of home educators.

However, please remember that anonymised data, including some quotes, will be shared as explained in the introduction, so only share in a way that protects your family's privacy.

(4a) Do you have evidence or reason to believe that your data has ALREADY been shared without your informed consent by health services with a local authority?

"Without informed consent" means without you or your child fully understanding what would be shared, who it would be shared with, the relevant consequences and implications, and without fully agreeing with these. It also includes if data was shared without the parent or child fully understanding or agreeing with the reasons for data sharing.

- Yes, I have evidence to indicate this
- Yes, I believe it has, but have no proof
- No reason to think this is the case

(4b) If your answer to the last question was yes – (a) or (b) - please select from the following list the type of health care service you know/believe passed on your/your child's information.

Please select all that apply.

- Hospital doctor
- GP
- Nurse
- Midwife
- Health visitor
- Dentist
- Optician
- Paramedic
- Occupational therapist
- Physiotherapist
- Speech and language therapist
- Psychologist or psychotherapist
- Admin clerk or receptionist
- GP surgery, individual responsible unknown
- Inpatient hospital stay, individual responsible unknown
- Outpatient clinic, individual responsible unknown
- A&E visit, individual responsible unknown
- Local health board
- Other
- Not applicable

(4c) If you believe your child/children's data has been conveyed by health care services to LAs without your/your child's consent, has this had a positive or a negative impact on your family?

- Very positive
- Positive
- Neither positive nor negative
- Negative
- Very negative
- Not aware of data having been shared

(4d) How would the potential of your family's data being shared without your consent with local authorities by health care services impact your trust in clinical care providers?

Knowing my data would or could be shared in this way would or has the potential to:

- Significantly strengthen my trust in those services
- Moderately strengthen my trust in those services
- Not affect my trust in those services
- Moderately weaken my trust in those services
- Significantly weakened my trust in those services

(4e) Do you believe that placing a legal duty on health care services to routinely share children's data with local authorities (without consent) would be likely to have an overall positive or negative effect on access to routine health care provision for home educating families?

- Strongly believe would have a NEGATIVE effect
- Believe would have a NEGATIVE effect
- No opinion/believe no effect
- believe would have a POSITIVE effect
- Strongly believe would have a POSITIVE effect

(5a) Have you had grounds to make a complaint or raise concerns about some form of health care service or staff member because of issues relating to home education?

If there have been more than one occasion, please select all that apply.

- Yes, I have made a complaint or raised concerns
- Yes, I have had grounds to make a complaint or raise concerns, but did not
- Not applicable

(5b) If you have made a complaint or voiced concerns regarding opinions or practice of health care professionals or services in relation to home education, did you feel this was appropriately and adequately dealt with?

- Yes, made significant improvement
- Yes, made some improvement
- Did not make any difference/did not feel was managed correctly
- Feel made the situation more difficult/worse
- Other

If you would like to provide more information on your answers to the last question on the outcomes of complaints/voicing of concerns, please do so here.

Please describe your experience in a way that protects your family's privacy, as previously explained.

(5c) If you felt you had grounds for complaint or to raise concerns, but did not, why was this? please share something of your experience, including why you did not feel able to do so.

Please select ALL that apply.

As these responses will be used as explained, please respond in a way that protects your family's privacy.

- I was concerned about potential or perceived negative effects of putting in a complaint or raising concerns
- I was not sure how to make a complaint or voice my concerns
- I did not feel it was worth the effort/I did not feel I would be listened to
- I was too busy to take the time/found the process too time consuming
- Process was too stressful
- Other

(5d) If you answered "Other" to the last question on why did not choose to make a complaint/voice concerns, or would be able to provide further information on your answers in that question, please share something of your experience here.

As these responses will be used as explained in previous questions, please respond in a way that protects your family's privacy.

(6) If you wish to comment further on the impact on home educating families of non-consensual data sharing of their data by health care services, please do so here.

Please remember that anonymised data including some quotes will be shared as explained in the introduction, so only share in a way that does not identify your family.

(7a) What do you feel would help prevent the kinds of situations referenced in this survey?

These are only a few initial suggestions, there will be space to add others in the next question:

Please tick ALL that you feel apply:

- Better EDUCATION/ADVICE about home education for health care staff from PROFESSIONAL BODIES that represent and advise them
- Better EDUCATION/ADVICE about home education for health care staff from DEPARTMENTS/SURGERIES/HOSPITALS/TRUSTS
- Departmental/practice/hospital/trust POLICIES that respect the privacy and autonomy of home educators and confirm that home education is not a safeguarding risk.
- Better advice for health care staff and policy development within health care services that respect the privacy and autonomy of FAMILIES IN GENERAL
- GOVERNMENT POLICIES that respect the privacy and autonomy of home educators and do not treat home educators with suspicion
- ABANDONMENT OF GOVERNMENT PLANS TO MANDATE NON-CONSENSUAL SHARING OF DATA about children by local health boards and GP service contractors.
- HOME EDUCATORS TO BE INVOLVED in construction of the education/advice/policies mentioned above to ensure they are appropriate, respectful and lawful
- Respectful and unbiased MEDIA representation of home education to better inform the community as a whole
- OTHER suggestions or comments – please share in next question.

(7b) Please add below any other suggestions or comments in relation to the last question on what could be done to prevent the kinds of situations addressed in this survey.

Thank you for your time.