

**TYPE 1 DIABETES AT SCHOOL &
UNIVERSITY: PPI WORKSHOP**

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Public Abstract

This report records the first Diabetes UK Patient and Public Involvement and Engagement workshop held in April 2021 discussing the privacy issues surrounding the use of personal data for research on the links between type 1 diabetes and education. This report is written in an informal and discursive style to reflect the collaborative and evolving nature of the patient and public involvement and engagement process. Things did not always go as planned, and we wanted to reflect lessons learnt and unexpected things that went well. This choice of style does not reflect any sense of undervaluing the contribution that the participants made or the impact these inputs will have on how data is processed or how research is conducted.

GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) Abstract

1: Aim

To ensure public views are addressed in the creation of an information governance framework for linking child disease-specific health datasets to school and university data for England and Wales as part of [‘The personal cost of health conditions in childhood’ project](#). In addition, to satisfy the patient and public involvement and engagement requirements of HRA CAG for Section 251 support.

2: Methods

To gather public views, a single, virtual workshop was held in April 2021 with eight members of the public with an interest in the issues for young people with diabetes in education settings. The workshop began with three presentations to participants, followed by small group discussions, each led by a Diabetes UK representative. Discussions had pre-planned topics and prompts. All participants were brought back together to ask further questions of presenters and share thoughts to the group on key discussion topics.

3: Findings

Feedback was broadly supportive of the use of confidential patient data without consent for research. In discussion we focused on three areas:

- **Focus 1 – ‘Privacy preserving data processing safeguards’:** While we tried hard to explain the different steps in the data processing, we knew in advance that it would be difficult for participants to grasp all of the details of the process and make a judgement on the suitability of the process in the limited time available (though a few of the participants demonstrably understood it very well). However, we feel most participants were satisfied with the general idea of how the process was used and happy that we were able to describe the safeguards in place to protect privacy.
- **Focus 2 – ‘Fair processing information’:** Concerns voiced were primarily beyond the scope of our research study, with participants frustrated that the data providers only provide materials online. Participants thought data providers could do more to tell participants that their data was being used for research, particularly for education data, including suggestions for something in classrooms similar to the GP posters for National Diabetes Audit.
- **Focus 3 – ‘Opt outs’:** Opt outs prompted the most questions, perhaps since this was the most easily understood process. There were questions relating to both data providers and our project; for example *“how can we opt out of projects if we don’t know our data is being used for research?”*.

4: Discussion and conclusions

The feedback was not directly related to the research design (though there was some helpful discussion of this too), rather we focused on how identifiable data (NHS number, name, date of birth, postcode) would be processed to facilitate the research. Workshop participants did not object to the proposed processing and provided useful suggestions for improving dissemination of information about the processing.

5: Reflections/critical perspective

It was challenging to gauge the extent to which participants understood the proposed processing of their confidential information. Given the importance of the research questions, there is also a danger that participants accept any processing on that basis. In future meetings it may therefore be helpful to discuss ways one might get a better sense of the limits of their support; for example, in relation to use of data by private companies.

Health Research Authority Confidentiality Advisory Group (HRA CAG) Abstract

Context

The patient and public involvement and engagement format was a workshop, held in April 2021, with presentations, breakout discussion groups and full group feedback. The panel included eight participants. The call and panel selection were weighted to boost males and minority ethnic participants (traditionally underrepresented in diabetes research). The group was overrepresented by Caucasian females with high educational attainment.

Summary of what was presented to applicants.

The first presentation, by Lucy Burgess, emphasised the benefits of the research, the use of unconsented administrative data and data linkage, and how this supports DUK objectives. The second presentation, by Alex Bailey, emphasised definitions of data types, which types of data can be used without consent under different circumstances, the law protecting CPI, why there is an exemption (S251), and how this operates. The final presentation, by Rob French, outlined the project aims, the potential benefits of the research, how data would be linked (data flows) and safeguards in place to protect security, provide information, and mechanisms relating to opting out.

Summary of the questions asked.

Discussion focused on three areas: (i) Understanding of the process for flowing data and the safeguards in place to protect privacy; (ii) fair processing and other information relating to the study and data; and (iii) mechanisms and information relating to opting out of data and the study.

1. Aim of the workshop

The aim of the workshop, held in April 2021, was to inform and seek feedback from people living with type 1 diabetes (T1D) on the principle of using their health data without consent, and to gather their insights on the processes that surround this. This is to inform the development of the '[Personal cost of health conditions in childhood](#)' project, being undertaken by Cardiff University (supported by ADR UK (Administrative Data Research UK) and DUK) which aims to bring together national administrative education and health datasets.

Specifically, we were looking for feedback from participants on the balance between the benefits and risks of sharing data for research with a focus on the following four questions:

1. Do you understand what is being proposed in terms of how we will use your data to link your health and education records?
2. Do you think the benefits of sharing and linking this data are important? Do you think there is scope to use these findings to help improve care and outcomes in education and health?
3. Do you think we have properly outlined the potential risks of sharing data? Are you satisfied with the safeguards put in place to protect your data?
4. Do you think the potential benefits outlined, outweigh the risks? Do you think this might not be the case for some groups of people with diabetes?

2. Methods

2.1. Prior to the event

The call

A call for participation was drafted (Appendix 1), seeking to recruit approximately 10 people with an interest in the issues for young people with diabetes in education settings.

In writing the call we were conscious of being honest to participants that while we would discuss the research questions around diabetes in schools and university, the key focus was on the information governance issues in the use of their data. We found that while this may have put off some participants, those that did attend were happy to focus on this, and the discussions were not unmanageably side-tracked into discussing other issues.

We stated that we were particularly keen to hear from four groups:

1. People with T1D who are in (or have recently completed) further or higher education.
2. Parents of children with T1D, health educators, specialist nurses or teachers working with people with T1D, and who have an interest in this area.
3. Healthcare professionals who have an interest in this area.
4. Those whose voices have not been represented in research, including from Bangladeshi, Pakistani, Indian, Black African, and Black Caribbean communities.

Inclusion focus 1: The call attempted to identify adults who would have the most recent experiences of schools and further/higher education, so focused on those in post-16 education since we wanted to speak directly to adults, who would be easier to contact and be of an age to consent to discussions.

While focusing on children who have progressed to further or higher education is part of our analytical sample, we are also interested in experiences in schools, but we are not including views on schools for those

children (or families/parents of children) who do not progress to further/higher education. The opinions on schools from our sample will therefore be those from individuals whom, for whatever reason, were able to have sufficiently successful education at school to progress to further/higher education. While we included parents in the call and did have one parent of a child with diabetes in school at the workshop, it may be the case that we need to supplement to add the views of young people who go on to pursue other avenues than higher/further education, including those who choose employment and apprenticeships.

Considering the other extreme, by focusing on young people at further/higher education we can speak with individuals for whom their memories of school processes are very recent, and relevant to current diabetes and school practices. However, we perhaps miss out on some of the deeper reflections on schools and university that students may have after they leave formal education and gain more perspective on how their time in education compares with employment.

Inclusion focus 2: We had one individual who worked in a school and was the parent of a child with T1D in further education, and another individual who worked as a paediatric diabetes specialist nurse and was the parent of a child with T1D in school.

Inclusion focus 3: Our focus on healthcare professionals should have had the highest response rate given that our call was shared most widely in academic/health networks, however we had low take-up from this group. Perhaps this group is better accessed through more formal channels – for example, mailing lists rather than twitter.

Inclusion focus 4: We were somewhat successful in targeting groups underrepresented in other diabetes patient and public involvement and engagement. This focus will be expanded in future workshop recruitment to improve representation.

Overall, the targeting of four different groups was an attempt to cast the net wide, to then select our group based on the responses we received. In future calls, we would be more targeted in the type of participant for a specific workshop, and be more ambitious in terms of identifying specific experiences that are underrepresented in diabetes patient and public involvement and engagement, particularly those with less optimal blood sugar levels (e.g. high HbA1c levels), and specific timing of diagnosis (pre-school; during GCSEs).

A £75 incentive was provided for each participant in line with the [INVOLVE guidelines](#). We hoped that this would help cover the individual's time. We did not seek feedback to what extent this helped individuals participate who may not have done otherwise, however we did note there was an increase in expressions of interest from young people after the payment was included in the information. Possibly, financial incentives may be more of a factor for young people (who are typically harder to recruit for PPI panels), than older adults who are joining because of a specific interest in the issue.

Recruitment of participants

Recruitment took place via the 'Diabetes UK Research' twitter account, with two tweets one week apart. We had 39 retweets and quoted tweets, including ones from influential researchers John Todd and David Dunger. We had 10 direct expressions of interest from the Twitter, of which six were part of the final workshop.

We also recruited through existing Diabetes UK networks (regional networks, Young Adults Panel, and research panels). This included a direct appeal to the Diabetes Research Steering Groups.

Of those expressing interest, one was an existing Diabetes UK Grants Advisory Panel member, one was a Type 1 Events volunteer, and two were connected with the Diabetes UK Midlands team. The remainder were contacts through the Twitter call.

Selection of participants

From the responses, 10 individuals with the most relevant experience were selected to take part, although only eight attended. This selection was primarily based on those currently in higher or further education or with other direct experience.

The group was highly relevant to the research sample and had some diversity amongst the participants:

- Six females and two males;
- Six from England and two from Wales;
- Six in higher education, plus a parent of a child in further education and another parent of a child in school;
- One postgrad student and five undergraduate students;
- Time from diagnosis ranged from 2-15 years.

We included two individuals who were not students: one paediatric diabetes specialist nurse who also has a child with T1D in school; and one educator who also has a child with T1D in higher education. Parents were placed in their own breakout group since we expected that including parents/educators/health practitioners may limit comments relating to other examples of those parties. This group brought an extra dimension to the wider group discussions as the feedback was from a very different perspective than the two student groups.

Pre-reading

Prior to the workshop, participants were provided with an agenda (Appendix 2) and a summary of the project containing: (i) background to the law on sharing data; (ii) a plain English summary of the proposed research; and (iii) a description of what we were trying to achieve in the patient and public involvement and engagement workshop (Appendix 3).

At the workshop we did not ask whether individuals had read the summary, and we did not have any comments or questions about the document from participants. In future we would ensure that this document is more succinct (1 page max) with an infographic to draw in the reader, and plan how to link that text to the discussion in the event.

Pre-discussion

We decided not to contact participants for 1:1 phone calls prior to the meeting. In hindsight it may have saved some time during the meeting to prime individuals and to ask for steers from participants prior to the event so that what we were presenting and reflecting some of their suggestions/feedback rather than starting with a one-way offload of information from us to them.

2.2. During the event

Dissemination

There were three presentations with time for questions and feedback. Both slides and videos of the full presentations are provided on the project [website](#).

Presentation 1: Lucie Burgess - Diabetes UK's strategic investment in data driven research

Lucie Burgess is the Diabetes UK lead for the national diabetes research data hub. She has broad experience with data driven solutions and diabetes related contexts. Lucie outlined the plans for the UK diabetes research data hub and how the proposed diabetes-education project fits with that work. Lucie explained the public and practitioner feedback that had gone into identifying the priorities for a diabetes hub. Lucie discussed the benefits of data-driven diabetes research at population scale, outlining some of the key datasets and the scope for bringing together diabetes datasets and cohorts into a single data hub. Finally, she described future Diabetes UK plans to support data linkage and the wider use of data, and how these align with the wider Diabetes UK objectives.

Presentation 2: Alex Bailey - legal requirements surrounding the use of health data in the UK

Dr Alex Bailey (MRC Regulatory Support Centre) gave a 20-minute presentation about the legal and policy requirements that apply to using health data for research in the UK. This focussed on:

- the legalities of using health data for research,
- the organisations involved in reviewing health research projects,
- the role of consent in health care research, and
- the differences between using data with consent and using data without consent.

A particular emphasis was placed on the role that the public and patients play in these processes.

Reflecting on this presentation, audience understanding of the topic might have been increased by explaining some of the routine NHS data flows and proceeding to explore when routine use becomes research. Some simple examples of research that that was undertaken without consent might have helped to provide context.

Presentation 3: Rob French - information on the proposed project, and how data would be processed

Dr Robert French is a senior research fellow in statistics at Cardiff University, with substantive expertise on the interface between child health education, methodological expertise in multilevel models for linked administrative data, and experience in the information governance issues surrounding the linkage of administrative health and education datasets without consent.

This presentation began by considering the scope of the research by showing the age coverage of the different datasets (education and diabetes) and how they mapped on to the life course of children and young people with diabetes. We then discussed the 'public benefits' of the research, including (i) improving statistical information; (ii) improving the evidence base for public policy; and (iii) improving quality of life and the economy. This was followed by a dataflow diagram to show how the data would be processed for the research, and some of the safeguards in place to keep data secure. Finally, we discussed further safeguards: providing information to participants and how patients might opt out.

Reflecting on this presentation, we feel the main issue is how to clearly convey what is done with the data, we had several discussions on this in advance of the meeting, including discussion of how to simplify the data flow diagram, which parts of the process to focus on etc., yet still there is scope to make things clearer. One way forward we discussed was perhaps creating some animated version of the dataflow – given the dynamic nature of the flows, this might help show only one part of the flow at a time and so make it easier to follow. One option suggested by the Cardiff University patient and public involvement and engagement lead was to do a workshop to allow participants to develop the animations, so they had patient voice. We discussed an event to do this for the 'stock' flows as a simpler first step, before extending it to data linkages.

Polls and word cloud

Informal polls were conducted during the presentations, and throughout the workshop, to gauge feelings. Results of all polls undertaken during the workshop can be found in Appendix 4. While we do not want to overinterpret these polls, which were primarily aimed to provide a breather and talking points for group discussions, it did seem as though we were able to make fewer participants feel uninformed about how their data was used. However, it also seems as though some participants no longer felt ‘very confident’, perhaps after we had shown that the issues may be more complex than they were expecting.

The responses to opt out were encouraging, though still a good number of participants did not feel confident in how they might opt out. Though we did not address this point directly in the discussion, it was part of the feedback on ways to inform patients – this is something to pursue further in future meetings. In the word cloud (Appendix 5) of open-ended responses to the workshop, it was gratifying to see ‘informed’ front and centre.

Participant discussion

The participants then moved into facilitated breakout groups to address the following questions:

- Open ended ‘opener’ question: What was your experience of schools?
- Do you think this project would benefit people with T1D in the long term?
- How do you feel about the section 251 processes that the researchers have gone through?
- Are there any surprises within the data flow? Would you change anything?
- Are the opt out process and opt out notifications sufficient safeguards?
- How would you feel if your own data were used in a study such as this?

Feedback from these sessions is described in the results section.

The presenters were not included in the group discussions to allow freer discussion.

Participant feedback

Participants then fed back and discussed in open plenary and were able to ask questions of the research team.

At the start of the workshop anonymous polls were conducted to assess how confident participants felt with their knowledge of health data in research processes. These polls were repeated following presentations from the research team.

Participant video feedback

Finally, participants were asked if they would be willing to record a short video reflecting on their experience of the workshop.

Three participants consented and provided detailed video feedback, which they have agreed we can share on the project website.

These videos emphasise the range of experiences and expectations of participants, we will seek to be more focused on how best to use participant videos in future sessions.

3. Results

Open-ended ‘opener’ question: Tell us about your experience of schools

- This question worked well to get participants talking, familiarising the group with each other, and starting discussion.
- The question allowed participants to share their own stories, giving space for participants to map the proposed research onto their own experience.

Do you think this project would benefit people with T1D in the long term?

- There was consensus within groups that the use of data in the way described would benefit people with T1D now and in the future.
- There arose a distinction between benefit as seen by researchers (improved data infrastructure, high quality data linkage, higher tax revenue from increased and longer employment, lower costs to the NHS of diabetes related complications) versus real-world benefits to the participants and people like them (more understanding by others of what they are going through, more support with managing diabetes in schools, earlier intervention at times of high stress). This could be explored further in future workshops.
- Participants focused on the benefit of bridging gap in educational experiences between children with T1D versus those without – “ensuring an equal playing field”.
- Participants reported a lack of knowledge around the impact of T1D on education, which they felt was likely to be large. They felt that a project of this kind could influence policy, and ultimately the education setting, which in turn could result in a better experience for young people. A related point was the hope for increased general awareness and understanding of how T1D might affect individuals beyond direct medical outcomes.
- There was a focus on diabetes-education interactions during transition from paediatric to adult diabetes care – this comes amongst many other stressful events that teenagers go through, not least of which were the GCSE exams.

How do you feel about the section 251 processes that the researchers have outlined in the presentations?

- Participants stated that from their perspective, the anonymisation was the key step in protecting their privacy.
- Participants expressed no reservations about the use of data without consent, however the feedback was that this willingness did not directly stem from the safeguards described in the presentations, or potential research outputs, but rather because of the potential real-world patient benefits. Participants were happy if the data flows would help people – if the benefits were less direct, the discussion may have been different.
- There was agreement that this approach could help ensure that the data is representative, capturing those who might usually be unlikely to take part in research, and this was deemed to be a benefit.
- Participants reported that they felt comfortable with their data being used and having T1D means that they are used to the concept of their health data driving clinical change.

Are there any surprises within the data flow? Would you change anything?

- Participants did not report any surprises relating to the data flow.

- Indeed, related to the point in the previous section that children with diabetes expect their health data to be used in research, they were more surprised to hear the number of studies which use their education data.
- Participants queried why this data was not being used for additional research questions for which they were interested, for example they asked with the current data why we did not look at the links between time of diagnosis versus timing of exams. They also questioned whether it would be possible to also include data on technology use to investigate the relationship with attainment. Finally, mention was made about including linkage to flash/CGM data, this is something we should return to, highlighting who owns their data when using devices, and the unwillingness of these companies to allow bulk downloads for clinical or research use. One might infer that this willingness to consider other questions and data flows shows a level of comfort (or acceptance) of data flows if they are now asking what else could be done in this space.

Are the opt out process and opt out notifications sufficient safeguards?

- Participants questioned details of the process of how someone might opt out if they wished.
- Participants stated that having this information in places relevant to the data used would be helpful. For example, within the GP practice or school. It was felt that posters in these locations would be helpful.
- Participants reflected on the complexity of this area and agreed on the need for any opt out process to be simple.
- A key response here was, if data subjects do not know their data is being used, how can they opt out. This applies to both data providers and our study.
- In addition to the potential use of data, participants gave equal weight to how individuals can get feedback on the outcomes of the studies conducted using their data. Again, they questioned how they can find these reports if they do not know their data is being used in the first place.
- Participants were happy that they were being given the choice to opt out. We did not directly ask whether individuals were planning to opt out, though none stated that they were considering it in the discussion.

How would you feel if your own data were used in a study such as this?

- There was strong support on the basis of the potential patient benefit.
- Participants were clear that they were happy for their data to be used if it resulted in real world changes which benefit other people.

4. Discussion

There were a broad range of views expressed, but we identified three themes which seemed to rank most highly with our participants.

Firstly, **participants gave strong support for the project and expressed comfort with the idea of the use of health data without consent in the specific circumstances described.** Future meetings might explore more carefully the limits of that support – for example, if the research was conducted in collaboration with a private company rather than a university (as may be the case for the CGM extension the panel suggested), would this change views?

Secondly, **participants were clear that their support was conditional on the research helping other people.** This project is asking people living with diabetes to take this on trust, but perhaps the research team should be able to provide something more substantial, to guarantee that this is not just going to lead to an academic report, but something more tangible. This might include specific details of how the research will be communicated more widely and outlining the mechanisms through which this might impact policy and practice. The project will consider carefully how we will develop this stream of communication, and also how we will feed back to the group at the end of the process so that we have credibility when we go to future panels stating that our research will have a real-world impact.

Thirdly, **there was agreement that the ability to opt out should be advertised in locations relevant to the data being used and that this should be explained in simple terms given the complexity of the area.**

Though this requirement falls more on the data providers than the research project this is something that we can pursue directly with data providers on behalf of our participants.

4.1. Limitations

We have discussed minor limitations and scope for improvement throughout the document, however in the discussion we identify three key limitations of the workshop that we aim to resolve in future meetings.

Firstly, despite working to improve the diversity of panel, we recognise that the panel was not fully representative of all the people in our study, and we will do more to improve this, particularly those who choose not to pursue further or higher education and those with sub optimal blood glucose levels.

Representativeness is a common issue across all diabetes patient and public involvement and engagement panels. For example, the DUK Young Adults Panel is made up of only 10% males, suggesting potential for more systematic changes in the recruitment process.

Secondly, we acknowledge that the flow of data is a complex area, which makes it hard for non-specialists to grasp the full process in a short period of time. We were prepared for this and chose to focus on specific aspects of the flows; ultimately, this is an issue that can only be resolved by committing more time to the group and reinforcing their knowledge and understanding of the process.

The third limitation follows on from the second. In setting the boundaries of the discussion, one is not able to shut down a speaker stating 'that is not our focus'. We must allow the participants to lead to the issues that are most important to them, which may not always be the same issues we expected or needed feedback on. We anticipated the possibility that participants may be more interested in the potential of the data and research questions rather than the less interesting topic of data flows. However, discussions also went beyond scope in criticisms of data providers used in our study, including the placement and content of their fair processing information. In the first instance we will pass this on to data providers; however, we are

also hoping to invite them to the next meeting to hear some of the feedback from the panel. When considering this limitation, we are also aware that, regardless of what the project requires, we still have to make the event interesting and relevant to participants, both to 'sell' the event to be of interest to potential participants and also to keep participants engaged and interested during the event itself.

4.2. Reflections – issues and what we will do to improve in future

Recruitment and participants

- Starting recruitment earlier would have allowed use of additional Diabetes UK channels and increased reach. We have given a three-month window to our next event and planning is underway to ensure that we can use the main DUK Twitter account for sharing the call.
- The small numbers for a workshop allowed in-depth discussion on this complex topic, but did present challenges with achieving diversity. Perhaps other options, such as surveys based on some of the feedback from the workshop, might be used to get a broader range of views.
- Participants reported a varying degree of baseline understanding which was positive, and a significant number had not volunteered for Diabetes UK previously. This is something that could be explored with 1:1 phone calls prior to the event to better prepare participants and tailor materials.
- Participants appeared comfortable with the requirements of the workshop suggesting that the call for participants and pre-reading had adequately briefed them.

Methods

- On reflection, an ice breaker at the very start would have been beneficial to get participants talking and confident to ask questions earlier.
- It would have been beneficial to have a breakout after each presentation to allow discussion of any questions to put to the research team at that stage.
- For the main breakout sessions – to allow sufficient time for discussion there would have been benefit in splitting the questions between the groups, so that different groups could focus on different topics.
- In diabetes we are very careful to use precise language, that is supportive and positive. We should be equally precise about the information governance language, so that all team members are using the terms anonymised, de-identified, etc. correctly, but also that we are not using language that makes it hard to follow. Agreeing the information governance language we will use (and not use) should be discussed before the next meeting.

Appendix 1: Call for participants

Type 1 diabetes and education

Overview

Children and young people with diabetes spend a great deal of their time in schools, further education, and higher education settings. While there is evidence suggesting that children with diabetes attain as well as their peers without diabetes, despite higher rates of school absence, there is still large unexplained variation in outcomes. Cardiff university with funding from [Administrative Data Research](#) (the government data linkage organisation) and supported by the [Royal College of Paediatric and Child Health](#) and Diabetes UK, are leading a new study to bring together national administrative education and health datasets, to support further research in this area.

Can you help?

We are looking for people with Type 1 diabetes (based in England or Wales) who are interested in the issues for young people with diabetes in education settings and would like to help us develop this study moving forward.

Initially we would be asking you to join a focus group on **6th April 2021 (10:00-13:00)** to find out more about the study and to share your views on the use of patient data for research in this area. At a later date you'd then have the opportunity to feed into the development of research questions.

We are particularly keen to hear from:

- People with type 1 diabetes who are in (or have recently completed) further or higher education
- Parents of children with type 1 diabetes, health educators, specialist nurses or teachers working with people with type 1 diabetes, and who have an interest in this area
- Healthcare professionals who have an interest in this area
- Those whose voices have not been represented in research, including from Bangladeshi, Pakistani, Indian, Black African, and Black Caribbean communities

Cardiff University will provide a £75 after the workshop to say thank you for your time.

How to register your interest:

If you're interested, please get in touch with Kamini Shah at kamini.shah@diabetes.org.uk to find out more about the dates and times and to briefly tell us why you'd like to be involved by 22 March 2021.

You can expect to hear back from us about whether we are offering you on the focus group by 26 March.

Please do not hesitate to get in touch if you have any questions or want to discuss any support or adjustments you may require.

Appendix 2: Workshop agenda

Type 1 diabetes and education workshop

Date: Tuesday 6 April

Time: 10am – 1pm

Time	Topic/Activities	Facilitator
10:00-10:05	Welcome and introductions	Anna Morris
10:05-10:20	Why is this important?	Lucie Burgess
10:20-10:40	Using data for research: navigating the system	Alex Bailey
10:40-10:50	Overview of the diabetes-education project	Rob French
10:50-11:10	What have we learnt so far?	Charlotte Austin
Break		
11:30-12:20	Gathering your feedback	Charlotte Austin
12:20-12:50	Sharing your feedback	Charlotte Austin
12:50-13:00	Closing and next steps	Anna Morris

Appendix 3: Pre-reading for participants

Plain English title: Using sensitive data for type 1 diabetes and education research.

Project title: *The personal cost of health conditions in childhood: Establishing the information governance framework for a research database of disease specific health datasets linked to administrative school and university data for England and Wales.*

Short information governance background

Background: In health and social science research which uses data, the priority for all academics is to adhere to the necessary safeguards which are put in place to protect the privacy of individuals. Universities, as publicly funded organisations, have a legal basis to use data for research (Article 6(1) of the Data Protection Act 2018); however, research that seeks to combine information for individuals from different datasets requires the sharing of more sensitive information – such as name and date of birth – between organisations, which has a higher threshold of confidentiality (common law duty of confidentiality).

Solution 1 Consent: One way to share such confidential data is to seek consent from the individuals represented in the data. However, when considering administrative datasets containing entire populations, it becomes infeasible, and bias due to self-selection into a study diminishes the value of a population-based approach. This is particularly important in health studies, where those individuals of most concern may not be attending clinics and so cannot even be approached for their option to be included.

Solution 2 Unconsented linkage: The Health Research Authority offer a set of approvals to share confidential information where consent cannot be obtained (known as ‘Section 251’, part of the National Health Service Act 2006). Typically, researchers seek such an exemption to answer a specific set of research questions (known as ‘Project Specific Section 251’), as we did in our current project linking the diabetes audits to education datasets for Wales. However, in this proposal we extend this to a special case of the exemption known as ‘Research Database Section 251’, since this allows the use of the linked data by other researchers, and also the scope to add further datasets related to diabetes or other health conditions.

Plain English summary

Background: Evidence on how children with chronic conditions such as diabetes, epilepsy, and asthma fare in spheres beyond health is limited, in part due to the challenges in combining administrative data described above. To tackle this for diabetes we worked with the paediatric and adult diabetes audits, together with HESA and Welsh Government, to flow and link these health and education datasets for Wales. This involved working with data providers, the Health Research Authority, and the Medical Research Council Regulatory Support Centre to ensure the information governance was of the highest standard and was well understood and supported by the data providers and other parties. Using this linkage, we were able to produce new evidence, which suggested that there was not a biological link between type 1 diabetes in educational attainment, rather it was other individual factors which were affecting both diabetes self-management and educational attainment.

Next steps: Our first diabetes-education data linkage for Wales highlighted some of the limitations of the current data, particularly with regard to unpicking the relationship between prior attainment and timing of diagnosis, which motivates our current application to improve the Welsh linkage and add the English data. In making this application for the new approvals, we seek to use the learning

from our Welsh linkages and extend the scope to (i) allow access for other researchers to use the data to answer new questions and (ii) allow researchers to use our approvals to flow more datasets for diabetes and other chronic childhood conditions for linkage with the education data.

Data linkages: We will link the paediatric (aged 0 to 16) and adult (aged 16 to 30) diabetes audits to the schools (NPD) and university (HESA) data for England using DfE as the processor for the identifiers and ONS-SRS as the secure repository. The equivalent linkages for Wales are already completed using (NHS Wales Informatics Service & SAIL), though we will use the new information governance framework to allow improvements to these linkages, adding pathways for access for other researchers and for flowing other health datasets. We expect to link 16,000 (0.4% of population) new English cases of type 1 diabetes (in addition to the 1,212 for Wales) with final school attainment (age 16), and approximately double this number linking to attendance data (age 6 to 16) and a similar number of cases for universities (mainly aged 18 to 21).

Overview of what we are trying to achieve.

The central task of our project is to set up the information governance framework (with the Health Research Authority Research Database Section 251 approval as the backbone) for the unconsented linkage of diabetes related health data to education data for England and Wales. The framework must satisfy all of the demands of the Health Research Authority, the data linkage repositories (Office for National Statistics and Secure Anonymise Information Linkage) and the data providers (NHS Digital, The Royal College of Paediatric and Child Health, The Healthcare Quality Improvement Partnership, Department for Education, Welsh Government, and Higher Education Statistics Agency). But most importantly (to us and the other regulatory organisations referenced here) we must satisfy the individuals who provide their data to NHS and educational institutions that the proposal meets the highest standards in terms of how the data is shared and that the benefits of this sharing outweigh the costs. The objective of this workshop is to inform a group of relevant individuals of the pros and cons and provide these opinions alongside our proposals to the relevant authorities.

Specifically, we are looking for feedback on:

1. Do you understand what is being proposed in terms of how we will use your data to link your health and education records?
2. Do you think the benefits of sharing and linking this data are important? Do you think there is scope to use these findings to help improve care and outcomes in education and health?
3. Do you think we have properly outlined the potential risks of sharing data? Are you satisfied with the safeguards put in place to protect your data?
4. Do you think the potential benefits outlined, outweigh the risks? Do you think this might not be the case for some groups of people with diabetes?

Appendix 4: Polls and Word Cloud

In order to enable reflection during the first half of the workshop, as well as evaluating the effectiveness of the three formal presentations (Lucie Burgess, Alex Bailey, and Robert French), three polls and a Word Cloud were created using Slido (7/8 responses for each):

Poll question	When	Purpose
<u>How would you rate your confidence in your knowledge of data research processes?</u>	Start of session (following intro by Anna Morris)	to establish a baseline figure of participants' confidence in their knowledge (as it would be challenging to quantitatively assess actual knowledge) ahead of presentations from Lucie Burgess, Alex Bailey, and Robert French.
<u>How would you rate your knowledge of data research processes? [repeat]</u>	After presentation	to establish the broad impact and changes in confidence of knowledge following presentations.
<u>Word Cloud: How do you feel about data consent?</u>	After presentations	to introduce a qualitative element regarding the broad topic of data consent ahead of facilitated group discussions.
<u>How confident are you in knowing how to opt out of a study like this?</u>	After break, before facilitated group discussions.	to recap final element of Rob French presentation regarding opt out safeguards ahead of a more in-depth discussion within facilitated group session

Appendix 5: Poll results

Poll One

Of 7 participants, 2 (29%) rated their confidence in knowledge of data research processes as 'not confident at all'. The remaining 5 participants were 'somewhat confident'.



Poll two

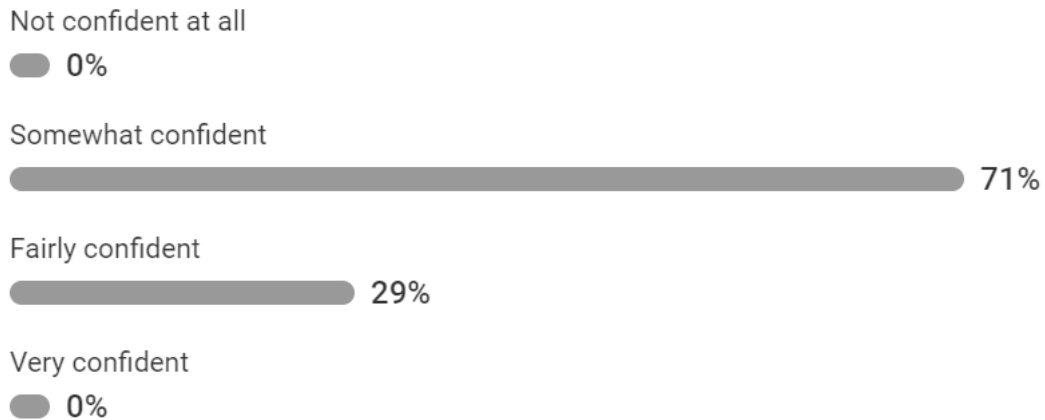
In this repeated poll (following presentations), 4 of the 7 participants (57%) rated themselves as 'somewhat confident' and the remaining 3 were 'fairly confident'. Following the presentations, none of the participants rated themselves as 'not confident at all'.



Poll three

Following Rob French's presentation which included details of how opt outs work within health research data, 5 participants (71%) said that they were 'somewhat confident' in knowing how to opt out of a study such as this. The remaining 2 participants (29%) were 'fairly confident'. This promoted further discussions amongst the groups.

How confident are you in knowing how to opt out of a study like this? 007



Word Cloud

A handful of themes emerged from this Word Cloud, particularly around the importance of data consent. One interesting phrase included was 'ok if used in research'.

