Opinions and Beliefs of Adults with Intellectual Disabilities or Visual Impairment about Research with Routine Care Data

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ABSTRACT

Research with routine care data (RCD) is not always a transparent process to the people receiving care for disabilities or impairment. This study aimed to understand the point of view on secondary use of care data for research from the people with visual or intellectual disabilities themselves. In total 36 participants from the UK and the Netherlands were interviewed (20 with intellectual disabilities, 16 with visual impairment). Transcripts were analysed inductively using the Framework Approach. Interview results showed that people from both countries and disability groups assumed that RCD research took place and saw potential contributions to care quality as grounds for legitimacy. Their themes of concern were about inaccuracy and threats to anonymity of data. Interviewees made suggestions for improving conditions under which RCD research can happen with informed consent. In addition to informing data governance policies of organisations serving people with disabilities, findings underscore the contribution that people with disabilities can make to data governance.

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INTRODUCTION

Technological advances in medical and mental health care informatics have led to a rapidly expanding field of studies to describe, understand, and evaluate health care through the lens of routinely collected care data. These high-speed developments and approaches are potentially useful for the field of (long-term) care for people with physical, intellectual, and developmental disabilities but also require critical discussion. The current qualitative study sought the perspectives of people with disabilities, receiving care and support in care organisations, about research on routinely collected care data. As the group with the highest stakes in those endeavours, it is important to include experiences, beliefs, opinions, and concerns of people with disabilities in the policy and practise of 'Big Data' research in long-term care.

Routinely collected or routine care data (RCD) can be a form of Big Data (Anagnostopoulos, Zeadally & Exposito 2016), because it provides large-scale and more or less structured data on practical, physical, psychological, emotional, and social-environmental parameters that are collected in processes of care on a regular basis (e.g., Glover et al. 2019; Horridge et al. 2016). Examples of RCD are recordings of incidents in residential care, journals on daily execution of care plans, and recordings of psychosocial requests or involuntary care. Even when taking into consideration the limitations and pitfalls of RCD, such as unstructured data and large proportions of missing data (Liaw et al. 2013; Wolpert & Rutter 2018), RCD analysis promises to be a fruitful source of evidence to improve complex care for people with disabilities (e.g., Schuengel et al. 2020; Schuengel et al. 2023).

Due to the low proportion of people with specific disabilities in the population and the practical challenges for accessing the population of people with disabilities, large cohort research studies are scarce in this field. Data linkage studies may offer an alternative (Reppermund et al. 2019), so that datasets that identify people with disabilities may be enriched with data collected in broader populations. Data linkage studies – in comparison with traditional empirical research studies – typically achieve large sample sizes, may provide a comprehensive set of features to study, are potentially representative for the population, and may not have such large problems with selection bias and drop-out as cohort research. Importantly, data linkage research does not require extra effort from participants to donate their time and energy in providing data (Reppermund et al. 2019).

Even though the use of RCD, including when enhanced through data linkage, may offer pragmatic advantages and reduced cost over the traditional ways to conduct research, it is also important to carefully consider this research approach in its social and historical context. RCD reflect an institutional perspective on what is important to record about the lives of people with disabilities and also the perspective of the organisations' staff (e.g., support workers). Some forms of RCD might have been initially designed to protect the rights of the people receiving care (e.g., records of involuntary care; Bakkum et al. 2023). However, if the institutional perspective is deficit-orientated, uncritical use of RCD may even maintain and support an organisational perspective, which would counter the efforts to conceptualise disability in terms of strengths (Albaum et al. 2021) and could mask structural problems such as prejudice and discrimination (Simpson & Thomas 2015).

This makes it all the more important to consider the pros and cons of this research approach from the perspective of people with disabilities themselves, as well as elicit their insights about using RCD responsibly and accurately (cf. Wolpert & Rutter 2018), thereby respecting their rights to be involved in any discussion or decision that concerns people with disabilities (UN 2006).

While previous work has focussed on making individual informed consent fairer and more inclusive (e.g., Jones 2021; McDonald & Kidney 2012), the current study focuses on the concerns that people with disabilities may have about research with data that is about them, but for which individual informed consent may not always be sought. This may be the case for research scenarios when consent is not formally required (e.g., in some circumstances when data are anonymised or pseudonymised). Under the *General Data Protection Regulation* for the EU (GDPR 2023) and similar regulations in other countries such as the UK, scientific research can be a legitimate interest for which the requirement for seeking individual permission can be waived in the case of anonymous data and data collected for public statistical or care purposes.

Legislative differences exist; for example, in UK regulations there is a higher threshold for regarding data as non-anonymous than in the European Union (IAPP 2022). Major differences also exist between care practices, law, and funding, like care related costs and benefits being reimbursed by insurance companies in the Netherlands for which care data have to be collected. Differences in regulations and laws between countries affect the use and relevance of RCD and are, therefore, a part of the context within which people evaluate and question the use of such data for research. It is, however, largely unclear how people who are the subjects of RCD regard the desirability and legitimacy of use of such data for research and to what extent their concerns and consideration depend on the context in which this is done (although see Andrews et al. 2020; Moody & Lugg-Widger 2017).

Taking an inclusive approach (Hayes, Gray & Edwards 2008), we explored the question of how people with two different types of disabilities think about using RCD for research purposes, and which considerations and messages they wish to send out to researchers and policy makers. We chose to study people with intellectual disabilities and with visual impairment, given that research with RCD is ongoing in these populations and given our long-standing relations with networks of self-advocates and experts by experience that would allow us to do the work. Exploration of thoughts, opinions, and experiences of people with disabilities was undertaken in a qualitative, inductive research design using semi-structured interviews, following a constructivist paradigm.

RESEARCH PROCESS

PARTICIPANTS

A total of 36 adults took part in this study (aged 18–72 years; $M = 42.4$, $SD = 14.7$; 47% female, see Table 1 for additional demographic information). Inclusion criteria were: adult age (≥18), intellectual disabilities (ID) or visual impairment (VI) indicated by receiving care or support from a care organisation specialised in ID or VI support, from the UK or the Netherlands, speaking English or Dutch respectively. Exclusion criteria were: youth under 18, people with limited or no verbal abilities, the combination of having VI and ID, and people who did not receive formal care or support. Our interview sample showed demographics representative for the populations of people with ID or VI, such as a higher percentage of supported living for people with ID, and a lower percentage of people with VI having a job or voluntary work (Table 1).

DEMOGRAPHICS	VI (n = 16)	ID (n = 20)
Job (or Daily/Weekly Voluntary Work)	7 (44%)	13 (65%)
Romantic Partner	11 (69%)	7 (35%)
Children	8 (50%)	1 (5%)
Supported Living/Within Residential Settings	0	13 (65%)
Number of Years Living in the Same Place Ranged from 2–43 Years		

Table 1 Descriptive Information about Interviewees with Visual Impairment (VI) or Intellectual Disabilities (ID).

There were 20 adults with ID (aged 18–72 years, $M = 38.5$; $SD = 15.5$; one participant preferred not to share their age; 45% female), of whom 10 were located in the Netherlands, in the central (urban) and eastern (rural) part of the country, and 10 in the UK, from London and the West-Midlands area. Intellectual disabilities was administratively defined in terms of receiving ID services in either country. In the UK, people with ID receive services from specialist community-based teams mainly of health professionals that work with people with ID usually within the National Health Service or from a variety of different (social) care arrangements including a few hours support in their own homes and supported living. In the Netherlands, people with ID receive services through care facilities and organisations which offer supported living, guidance with daily activities, a day programme, and if needed treatment for physical or psychological problems. Care may also be ambulatory, when people receive visits from a care professional for several times a week or month, for example for guidance and psychosocial support. In the Netherlands, people with borderline intellectual functioning and adaptive functioning

difficulties are also eligible for such long-term care and are included in the population of people with ID (Woittiez et al. 2014).

There were 16 adults with VI (aged 25–63 years, *M* = 47.1; *SD* = 12.5; 50% female) who took part, of whom eight were located in the UK. Because adverts for participation were placed online we reached people located across both countries, living in urban and rural areas. For this study, having a VI included low vision and blindness. It was defined as an impairment in vision which, even after assistance from visual aids, still affected a person's daily functioning (Heppe et al. 2020). Care for people with VI is usually ambulatory. It consists of several visits per week or month by a care professional, for example, for mobility training or support in the home with assistive devices, or psychosocial support. A relevant systemic difference between both countries was that in the Netherlands, care and support for people with VI or ID are mainly subsidised by the government or funded by health insurance companies. Health insurance companies are not central to the UK health care system and were therefore not mentioned by UK interviewees.

PROCEDURE

This study was approved by the Ethical and Scientific Committee of VCWE at the Faculty for Behavioural and Movement Sciences at the Vrije Universiteit Amsterdam in 2019 (VCWE2019–115). We interviewed people with disabilities, either visual impairment (VI) or intellectual disabilities (ID), and organised feedback rounds for these interviewees to discuss the outcomes and discussion as formulated by the researchers.

Interviews were organised with people with ID who were recruited through several care organisations with established self-advocate groups for people with ID in the UK and the Netherlands. The people with ID in the Netherlands came from one large care organisation with three participating locations in the central and eastern part of the country. The people with ID from the UK came from four participating care organisations located in urban and rural areas. People with VI were recruited through online advertisements, social media, and online platforms for people with VI. They used audio supported software, such as screen readers and assistive devices, such as braille keyboards, to read online messages. Also, most websites and social media platforms have various features such as zoom and contrast to make messages accessible to people with VI. The impact of the VI on the interviewees' daily functioning was mapped out in the first part of the interview by asking questions related to characteristics of the impairment, mobility, and the use of assistance aids assistive devices. This resulted in a heterogeneous population of participants who were either blind from birth to participants with low vision who just recently lost their vision. However, all participants did receive some type of care or support for their VI and were familiar with the care provided to people with VI in their country.

All interviewees provided written consent before the interviews, after having taken the opportunity to ask their questions. The interviews with people with ID were scheduled with the help of a care professional from their organisation, who could help with managing their calendar, and administered at locations of care organisations in a private room. Care professionals were not present during the interviews, to enable people with ID to speak freely about their opinions on the care organisation and the services they received. The interviews were audio recorded for analysis purposes, after consent by each interviewee. The interviews with people with VI were administered over telephone, using a voice recorder device, after consent by each interviewee. Interviews varied from half an hour to two hours depending on the amount of elaboration by the interviewees on their opinions and beliefs. Interviewees were provided with €10 or £10 compensation.

Finally, a feedback round was organised for the interviewees to discuss the initial analysis of their interviews. Researchers organised the feedback rounds for interviewees and self-advocates with ID at four locations of care organisations in London, and within the Netherlands. In each feedback round three to five people participated. Due to the outbreak of the COVID-19 pandemic, these feedback rounds within the Netherlands were held via online video calls. The feedback round for interviewees with VI was held via e-mail by sending out a draft summary of the results and the overall conclusion of the study. The people with VI provided written feedback using accessibility aids like braille, enlargement, and voice-software.

INTERVIEWS

A semi-structured interview was developed to explore the opinions, thoughts, ideas, and beliefs of people with ID and with VI about the use by researchers of RCD, for research, that was originally stored in their care organisation's files. The interview consisted of four parts with 27 questions in total for the interviewees with ID and five parts with 28 questions in total for the interviewees with VI. The interview and its order of questions was progressively difficult in terms of its design, starting off with easy questions for every participant. Researchers made the decision to include the most cognitively demanding topic containing questions about 'follow-up studies' at the end of the interview, to prevent early dropout. Questions about follow-up studies proved inaccessible for people with ID; responses to these questions are therefore from people with VI only.

The interview protocol was developed in English by our team, which included two native English-speaking researchers. The interview was then translated into an easy-language version because of the communication needs particularly of people with ID. For validation, this version was double checked by two additional researchers who were experienced in working with people with ID both in care organisations and in research. After establishing the interview protocol and the easy-language version, these were translated into Dutch versions, and back-translated for a validation check. Supplementary Material includes the interview description including the core topics: 'data and information', 'research and data use', 'sharing data', 'linking data', and 'follow-up data in longitudinal studies'.

DATA ANALYSIS

We followed the five stages of the 'Framework Approach' described by Ritchie and Spencer (1994) for inductive analysis of the data: 1) familiarisation; 2) creating a thematic framework; 3) coding the text ('indexing') to identify which parts of the text relate to which part of the framework; 4) summarising these data to reflect the framework ('charting'); and 5) trying to make sense of these data through mapping of concepts and interpretation of meaning ('mapping and interpretation'). This method is a familiar and valid method in the field of applied policy research (e.g., Cullen and Lindsay 2019; De la Croix, Barrett, and Stenfors 2018).

Data from the semi-structured interviews were the building blocks for the themes, which were structured into the following coding categories: Knowledge on Data/Information Storage, Personal Experience, Opinions on Routine/Big Data Use, Ownership, Weighing up, and Conceptualisation. This thematic framework as shown in Table 2 was developed by the two lead researchers (first two authors) after finishing all interviews with people with disabilities. Therefore, the framework resulted from, thus could not guide, the conversations with interviewees. The quality of the framework was checked by a first round of reading through the experiences, feelings, ideas, and opinions of the interviewees by the two main researchers, and in a second round by a third researcher (third author) who also interviewed participants in the Netherlands.

All three main researchers were Dutch of origin with a professional level of English language. All steps of this research were conducted in close collaboration with two native English-speaking researchers in our team. Dutch transcripts were translated by the two main researchers into an English document that was used for stages 4 and 5 of the Framework Approach: charting, mapping, and interpreting all the answers together. Discussing the meaning of all responses and checking the correct translation of the Dutch data with the third researcher supported reliable and valid outcomes at stage 5 of mapping and interpreting the results. The content validity of outcomes as discussed by the researchers was then established by performing a feedback round checking the thematic outcomes and the framework approach with the (English and Dutch) interviewees themselves and their support workers. The feedback was used to refine the original formulation of the results, such that small corrections were made to form or formulations, but the meaning remained the same. Illustrative quotations in the Results are referenced to participant pseudonyms.

RESULTS

Table 2 shows the themed coding categories and indexes from the final stage of the framework approach. Indexes represent the sub-themes found in the opinions of people in our interview data. The most prominent and general message of both disability groups and countries was presented first, followed by the subsequent themes in interviewees' answers using the coding categories and indexes from the Framework.

FRAMEWORK CATEGORIES	QUESTION NUMBERS	QUESTION NUMBERS	INDEX (SUB-THEME)	QUESTION NUMBERS	QUESTION NUMBERS
	VI per Category	ID per Category		VI per Index	ID per Index
Knowledge on Data/Information Storage	6, 7, 8, 9, 10, 11, 12	7, 8, 9, 10, 11, 12, 13	Practicalities of the Data	6, 7, 10	7, 8, 11
			Reason for Routine Care Data	9	10
			People Access	8, 11, 12	9, 12, 13
Personal Experience	13, 14	14, 15	Personal Experience	13, 14	14, 15
Opinions on Routine/Big Data Use	17, 22, 28	18, 23	Storage/Sharing	17	18
			Linking	22	23
			Follow-up	28	
Ownership	15, 18, 19, 23, 24, 28a	16, 19, 20, 24, 25	Feelings of ownership	15	16
			Decision making	18a, 19, 23, 24	19abc, 20, 24, 25
			Permission	18bc, 23ab, 28a	19de, 24ab
Weighing up	20, 21, 25, 26, 28b, 28c	21, 22, 26, 27	Advantages/ Benefits	20, 25, 28b,	21, 26
			Worries/Concerns	21, 26, 28c	22, 27
Conceptualisation	3, 16, 27	3, 6, 17	Personal Disability Concept	3	3
			Definition and Meaning	16, 27	6, 17

GENERAL OPINION ABOUT USING ROUTINE CARE DATA FOR RESEARCH

Interviewees with either visual or intellectual disabilities and from both the UK and the Netherlands expressed their support for the use of RCD for research to improve care and support services. Several people even spontaneously expressed 'what a good idea!', based on their understanding and belief that data sharing and linking could lead to better insight into the *effectiveness* of care, support, and therapies and, therefore, improve the quality of care for everyone with similar disabilities.

Some interviewees stated, 'I would be happy about that, that would be okay' (VI-UK03) and 'If it helps to improve care, then I am willing to participate' (ID-NL10). In addition, several people expressed to the researchers that the inclusion of people with disabilities into any care process is important, and that RCD should be used as well to help change society's views on

inclusion. Research with routine care data could help in changing society's views by presenting data on people with disabilities. Sharing more information about people with disabilities (e.g., showing data about their daily work activities as an example of their contribution to society), or using RCD to directly improve care in general, could help society to notice them more. One interviewee voiced their opinion beautifully about this theme: 'We have to change society to view people with disabilities, not just people with learning disabilities. Because unless we do, they become less valid, they are not considered valuable, as if they don't give anything to society, but we do' (ID-UK01).

Importantly, several interviewees thought their current data were already being used by the organisations and by researchers for the sake of care and support improvement, even when at that point, this was not happening with data from their own care organisation. Some of the interviewees also felt a lack of control in the decision to use RCD, commenting that researchers will use their data anyway.

DIFFERENT OPINIONS BY PEOPLE WITH VI OR ID ABOUT SHARING AND LINKING DATA

Opinions about sharing and linking care data were differentiated in nuanced but important ways. Most people with VI or ID and from both countries were happy with sharing RCD as long as it was for research purposes. Interviewees were more hesitant about agreeing to data linking compared to data sharing. Some people with ID (but not VI) were less certain about linking RCD to other data for research, whereas they were positive about sharing RCD for research. It seemed that some people with ID found the idea of data linking more complex, not only to understand for themselves, but also to carry out for the care organisations or researchers. One interviewee said, 'I think if they are going to do this, it will become way too much paperwork' (ID-NL08), while another said, 'The person should talk with their supervisor and ask their supervisor whether he or she thinks it's a wise thing for them to give the information to the organisation. [Which organisations?] I don't know about organisations, I don't know a lot about that' (ID-UK08).

We did not find this complexity issue about 'Linking data' for the group of people with VI, as was found for people with ID. But people with VI wanted to take more time to consider this more unfamiliar option with regards to upsides and downsides, and finally concluded for the most part that they would not object to research with RCD, whether linked or not:

> I think in principle, I would want much, much stronger safeguard in place. So that I have the confidence, so I think it opens up a lot more scope for misused data, personal data. I know they don't share that information with anybody else, but I've seen when once information is moved to another organisation, that connection disappears. The original documentation about what and where that information could be stored and used, very often tends to be lost and or deliberately ignored. (VI-UK03)

OWNERSHIP AND WEIGHING UP: CONDITIONS FOR USING ROUTINE CARE DATA FOR RESEARCH

Permission and consent

An important condition for almost all people in this study was to be asked for permission before storing, sharing, and linking RCD for research. Interviewees also made suggestions how permission could be obtained, including opting out. Importantly, almost all interviewees expressed they would often or always agree and give permission for their data to be used for research, as long as they were actively asked first and informed about the purpose and goals of the study: 'As long as they ask me, yeah. And brought me in on the research. I think if information is going to be shared – and it needs to be shared – it needs to be done sensitively and with permission' (ID-UK01).

A difference on this issue was found between interviewees with VI and ID, in the sense that several interviewees with ID expressed they would not mind if people from the care organisation or researchers looked into their data for purposes of planning care or conducting research. Suitable purposes were seen as studying people's experiences with the care provided,

or guiding care and support improvement for themselves or others with similar disabilities. People with VI did not express these opinions or feelings about easily letting people from the care organisation have a look into their data, giving the researchers a sense of more hesitancy. Several interviewees with ID also mentioned they would want to discuss new research studies briefly with their key support worker or a family member before providing permission. They thought that this would most probably have a positive impact on them, being more likely to provide permission. Discussions with others about providing permission were not mentioned by people with VI.

Several interviewees with VI volunteered suggestions for dealing with having to ask for permission from large numbers of people for multiple studies. Some people with VI thought that the process of providing permission (downloading, reading it through, signing, saving, and sending back the permission form) could be challenging for people with VI. Opting out (passive consent) was mentioned as a possible solution to overcome the difficult process of providing permission for large studies using RCD. Interviewees with VI expressed this would be especially suitable for studies with anonymised data. Some people with VI also believed that opting out was the only solution for providing individual permission for this type of research. They were under the impression that the current legislation was that researchers were obliged to seek individual active consent when using care data in any form (which stands in contrast to exemptions for particular data types and situations in the *General Data Protection Regulation* in the EU).

Recurrent permission and consent

Another theme involved the difference between giving general permission for all future RCD research at once, or giving specific permission every single time, for every single organisation. Most interviewees with VI and some interviewees with ID said they would want to be asked for their consent on all RCD research only once. People with VI mostly said that providing permission for every new study or every new organisation could confuse people and could take up too much time from both participants and the researchers. In line with this, almost all interviewees with VI said that they would want to be asked for permission for research by one main organisation or coordinator, and not by all other (care) organisations separately. One interviewee said, 'One will do, as long as they tell me where the information was going' (VI-UK04) and another said, 'One will probably be easier, probably the one that I have close direct contact with' (VI-UK07). Still another considered the burden also for researchers: 'Once. When you would have to give permission every single time, then I would think: 'Now what's it about this time? That just seems unnecessary. Also, for the researchers that wouldn't be doable' (VI-NL05).

There were also some interviewees with VI and more with ID who insisted on providing permission every single time for every study, as they felt they should be the ones in charge to decide with whom and specifically which data can and cannot be shared for research purposes. One interviewee expressed this as follows: 'Together, if they want to share information about me they all need to ask it. Yes. If they need to change something, they need to ask me before' (ID-UK06).

Solutions for asking for permission and consent recurrently

During the interview, after several questions and thinking through the benefits and downsides of recurrently providing permission for all research studies and all organisations, several of the interviewees with ID also came up with solutions. Interviewees referred to the possibility of discussing and reconsidering this regularly, saying 'If it is registered, then you can do it once and then after a couple of years again' (ID-NL10) and 'I think it could be once a year maybe. At a personal meeting, when my parents and support workers sit together. 'Listen, about the data, do you want that?' (ID-NL03).

Others suggested the possibility of broad permissions that would extend over a limited number of years:

> If they say in the beginning that the research will be about a broad range, one time on this subject, then that... Then they have been clear from the beginning that it's a broad research there will be multiple aspects of my life that they'll use. Then I'm happy to give permission just once.' (ID-NL05)

Just stay within the GDPR law. Then I would say, like, make one standard form for about four or five years. Doesn't matter for whatever research, or other things, for better care, just one standard form. So you don't have to sign everything all over again. (ID-NL08)

Opting out – especially telling a support worker that they did not wish to be included in any or a specific research project – was also mentioned by multiple interviewees with ID and VI as a solution for providing permission for data sharing and linking. When thinking about follow-up studies, a suggestion was sharing the permission in general for all universities: 'In which building this would happen doesn't really matter to me, whether it is the University in Amsterdam or in Utrecht or… That wouldn't matter, they could even share it [permission] with the other' (VI-NL03).

Anonymity and privacy

The second important condition suggested by several interviewees for RCD use in research was the guarantee of anonymity and privacy of the data. Opinions varied between the disability groups. In general, the interviewees with ID stressed that anonymity and privacy were very important to them, but they often also believed that this would be guaranteed by the researchers when they inform participants about those procedures. One interviewee said, 'My name won't be on it, because you said that it won't' (ID-UK01). Only a few interviewees with ID expressed scepticism about support workers or researchers effectively protecting their privacy. One interviewee said 'I think that, because of my privacy, they can't use my name. But the problem is that you are never 100% sure if they do it. I can't check that' (ID-NL03).

Interviewees with VI were in general more sceptical about the guarantee of anonymity. The main reason for worries and scepticism was related to the low incidences of visual disabilities within most populations. It is difficult to guarantee anonymity for a low incidence population, because using only a few data points – geographic location and the use of specific assistance aids such as a guide dog – could lead to traceability of people with VI. Therefore, these interviewees said they would rather not share certain data for research. Interviewees with VI who did not explicitly mention anonymity issues generally talked about sharing and linking RCD, assuming that these data would already be anonymised: 'I think my support worker could look into my data, for the sake of my treatment. And supposedly someone else, well I don't know if they can still subtract my anonymised data, but I would say I would have to give permission for that first' (VI-NL05).

Data ownership

Almost all interviewees were clear about RCD being their data. Most interviewees with VI first suggested that they never really thought about this issue, and then on second thought believed the data belonged to them. Some interviewees with ID were also very direct and passionate in their answer saying, 'Mine! I sure think so' (ID-NL09), 'It's mine. It's about my life' (ID-UK01), and 'First of all mine' (ID-NL02).

Several interviewees with ID expressed on reflection that they believed the data could or would also be partly owned by the care organisations to be able to help all the people receiving care; only one person with VI agreed with this. For interviewees with VI, the initial strong opinion on ownership was rarely expressed, but every interviewee in one way or another expressed that they considered themselves the owner of the data, for example:

Who owns it? Well it's my information, I can always ask them to remove it, I have rights I think, to remove it. It is technically mine, but I kind of lend it to them to caretake it in a way I suppose, they caretake my own information. It is still mine at the end of the day. They can't do anything with it without my say so. (VI-UK07)

WEIGHING UP: WORRIES OR CONCERNS ABOUT DATA SHARING AND LINKING

The next theme regarded worries or concerns about sharing and linking RCD for research. There were mostly similarities between all interviewees including the previously mentioned

anonymity and privacy issues. In addition, some specific differences were found between the views of interviewees with ID or VI.

Identity theft

A concern about identity theft came up with some interviewees with ID, mostly from the UK. The worries about identity theft were sometimes described by interviewees with ID as if they had seen this type of incident happening on (social) media or television. One interviewee said 'If third parties use it for their own ends. With criminal intent, id theft [identification document] for example'. (ID-UK03). None of the interviewees could give a witnessed example. The interviewees linked these 'rumoured' incidents to the possibility of someone doing the same with their personal data or RCD:

> Yeah, maybe that people would run off with my information. That they would use me for, like fake profiles or anything like that. Yeah that happens quite a lot. That they just put a fake company on a letter with: 'Research has started, sign here', things like that. And then imagine when you sign, well you know, they can just do whatever with your information. (ID-NL06)

Risk of benefits being cut

The concern about risking their welfare benefits being cut when sharing RCD for research was only expressed by interviewees with VI, albeit multiple times and clearly stated as an important factor. None of the interviewees with ID expressed such worries. There was also a country difference. Interviewees with VI from the Netherlands were more concerned about the accuracy of the data, such as being outdated or underreported, and interviewees with VI from the UK were more concerned about having their benefits cut. National care systems operate differently in each country, and this may influence how interviewees viewed organisations like insurance companies (relevant to health care in the Netherlands) and governmental institutes and their financial systems through which people receive aid or care. Interviewees with VI from the UK expressed more scepticism about how services are distributed throughout the country. Interviewees with VI in the UK more often expressed having experiences of their benefits being cut or having negative experiences with service providers compared to interviewees with VI in the Netherlands.

In general, fears amongst interviewees with VI were that RCD study findings would be used against them by care organisations, health insurance companies (in the Netherlands), or governmental institutions. There were worries about how RCD would be used to create insight into the costs and benefits of specific VI-care or assistive devices. Interviewees suggested that due to the heterogeneity of the population, studies using RCD should not only be used to provide insight into the overall population with VI but also subpopulations. Some Dutch interviewees with VI were also afraid that releasing care data for research could lead to studies focussing on aggregating data to generate profiles for 'typical' care users rather than promoting an understanding of individual variability to inform VI-care:

> I think the insurance company could – this is what I'm afraid of – link all those kinds of data, like creating some sort of norm. So, a sort of average blind person, which you don't want to be [...] Like it could also tell you, what does someone use, how many canes a year does someone need? Will I suddenly not get what I need, or maybe I'll get stuff I don't need? (VI-NL05)

With regard to follow-up studies using RCD, most interviewees with VI from the Netherlands and some from the UK were concerned about whether the data would still be accurate, correct, and up to date when data were collected a few years before. For some people with VI their visual disability is not stable; it changes over time, as does how they participate in society. Moreover, the introduction of a new assistive device could dramatically change outcomes. Therefore, interviewees worried this could have an impact on the usability of the data. This concern was also often linked to the concern of using care data to cut benefits, because a selection of care data could lead to more positive findings and, thus, a false picture about a lesser need for care.

DISCUSSION

Interviewees with visual or intellectual disabilities understood and broadly supported the need to use RCD for research. Their opinions about using and sharing RCD for research were generally positive, as long as specific conditions were met. These conditions included permission and consent, anonymity and privacy, and clarity about data ownership. Interviewees were willing to share RCD when the main goal of the research is to improve care and support services for people with disabilities. There was a strong view among interviewees that routine care data belong to people with disabilities themselves, and that they therefore have to be asked for their permission (which is possible in various ways) for data to be used. Also, it was seen as important that the anonymity and privacy of their data are guaranteed. Interviewees also wanted to be included in the research process from the outset, during goal setting, and in discussions or decision processes about research.

These findings could alert researchers and policy makers to issues in doing research with RCD that have as yet received limited consideration, especially with regard to perceived ownership of data. To accommodate the views expressed by interviewees in this study, especially their sense of ownership, a shift of perspective may be needed for RCD research.

The themes from the interviews may be interpreted against the background of existing theory on self-determination, agency, and basic psychological needs and strength-based, positive psychological perspectives in general (Simpson & Thomas 2015). To start, the generally favourable attitude towards using RCD for research may be driven by the basic psychological need for relatedness, which includes feeling significant to others (Ryan & Deci 2000). Such significance may derive from seeing oneself as helping or looking out for others, especially those with whom one shares similar disabilities. This general willingness to be included in Big Data may also be perceived as a form of social inclusion (Bates & Davis 2004; Hayes, Gray & Edwards 2008). Several people expressed that they – as people with disabilities – wanted to be seen and represented in RCD research, and that research should not only represent data from the general population but also people like them, with an eye towards improvement of care for everyone with disabilities.

The motivation to contribute, help others, and be included may be counteracted by the basic need for autonomy (Ryan & Deci 2000) when people perceive lack of transparency and control over what happens with what they perceive as being 'their data'. Concerns about control might explain why linkage of data from one source to another met with more resistance than research on discrete sets of RCD. The more complex issue of linking data was met with negative responses, emphasising loss of control, followed by hesitancy and worries. Interviewees required more information and explanation before they could formulate opinions. Discussion of data linkage may therefore have been perceived as a context that would frustrate the basic need for competence as well as autonomy (Ryan & Deci 2000), inducing an aversive response.

When discussing the issue about asking for permission recurrently, researchers experienced that the interviewees who worried about this more strongly felt the need for checking and controlling the process of using and sharing RCD for research. The interviewees expressing this need were often the same interviewees who mentioned negative experiences with support workers, feelings of mistrust, or feelings of not being cared for properly by their care organisation. Experience-dependent attributional bias towards potentially malignant intentions (Dodge et al. 1990; Huesmann 1998; Miller & Johnston 2019) may therefore be an important factor to consider when asking for permission, especially if such permissions have a wide scope such as blanket permissions for using data at admission to a care provider.

Specific knowledge regarding risks associated with personal data may explain worries held by some interviewees with ID about identity theft, or names being used resulting in loss of anonymity. Repeatedly being presented with (visual/online) examples of identity theft may result in a cognitive bias as well and lead to worries about one's own data being used, especially in combination with low self-perceived digital literacy (Khanlou et al. 2021). Interviewees appeared to wrestle with the dilemma between personal risks involved in sharing their data and opportunities to contribute to the common good. Interviewees with VI did not voice concerns about identity theft when sharing and linking data. They were mostly concerned about benefits being cut back and anonymity not being guaranteed because of the (extremely)

low prevalence of vision loss in the population. We speculate that concerns about potential adverse consequences of research with RCD may not only derive from experience but also from societal awareness.

Finally, the interviews and feedback sessions demonstrated that, at least in the context of hypothetical scenarios, productive dialog took place between people with disabilities and researchers despite the threatening nature of the privacy incursions and other risks that came up. Interviewees started generating potential solutions for practical problems and dilemmas, they actively engaged with finding solutions to risks and burdens relating to RCD for research; this was more often found for interviewees with VI but also some with ID. Participating in devising and overseeing such solutions by the interviewees with disabilities might therefore contribute to empowerment of people with disabilities with respect to research.

LIMITATIONS

As a qualitative study, findings are not readily generalizable within and across populations. Several of the views expressed came from self-advocates from research groups for people with intellectual disabilities. There were no interviewees with VI from self-advocates or research groups in this study. Being a self-advocate or being part of such a group in itself is a selection bias for our study, because these people are already keen on talking about research, have more knowledge about research topics than peers, and have practised on forming opinions, ideas and worries through their discussion groups. We sometimes found comparable ideas or opinions of people with ID from the same research group, such as the identity theft issue, which may have been a previous discussion topic for them. Indeed, during the feedback rounds the professionals supporting self-advocates with ID in the UK mentioned that quite recently 'internet safety' and 'identity theft' had been part of their conversations with the self-advocate research groups. Nevertheless, these concerns are important to take into account when providing information about new research (with RCD), ensuring privacy and anonymity, and asking for consent.

Although multiple people from the same research groups participated, the fact that we recruited a number of such groups meant that we still had interviewees varying in age, gender, disabilities, background, and from different organisations, locations, and two different countries. The common themes identified across such heterogeneous samples support their relevance for ongoing discussions about sharing and linking routine care data relating to adults with disabilities.

IMPLICATIONS AND CONCLUSIONS

The views of interviewees with disabilities about using RCD for research reflect a desire for more rights than they currently have according to existing regulations such as the *General Data Protection Regulation* (GDPR) for the EU and medical care data acts in The Netherlands (RIVM 2023) and the UK-GDPR (Information Commissioner's Office 2022).

The desire for acquiring more rights may not only have implications for future amendments to laws and regulations but also more directly for research taking place under the current frameworks. From a research ethics perspective, the findings present researchers with new ethical dilemmas: should a researcher use the maximum amount of discretion under the law (which is based on a democratic process that balances individual rights and the common good), even if that would overstep the boundaries of what individual people with disabilities may see themselves as fair?

In situations where researchers are legally exempt from asking for individual informed consent for using these data, it is not always clear what the research ethical and regulatory frameworks are within which these data may be used responsibly and fairly. It may be important to study the extent to which studies with anonymous or pseudonymised data are routinely submitted for research ethical review, whether ethical review boards include the perspectives of people with disabilities, and if so, how. The current study underlines the importance and feasibility of including people with disabilities themselves in discussing the ethics of research studies and practices and working towards resolving some of the dilemmas arising.

Findings of this exploratory, qualitative study thus pose critical questions for current practices on research with RCD for improving care and support for people with disabilities. While country-specific legal regulations and ethics may vary, the opinions and ideas of the people with disabilities themselves should be at the forefront in research discussions about sharing and linking routine care data.

DATA ACCESSIBILITY STATEMENT

The interview data that support the findings of this study are available on request from the corresponding author, dr. Maaike van Rest, m.van.rest@vu.nl. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

ADDITIONAL FILE

The additional file for this article can be found as follows:

- **Supplementary File 1.** Interview description. DOI: https://doi.org/10.16993/sjdr.1045.s1

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The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Dr. Maaike van Rest co-constructed the research and interview protocols, collected data, analysed data, and collaborated in writing the main body of text for submission and revision of the article.

Dr. Eline Heppe, co-constructed the research and interview protocols, collected data, analysed data, and provided feedback to the article.

Richtje Ras, MSc., collected data and provided feedback to interview protocol and article.

Dr. Mairi-Ann Cullen provided feedback to interview protocol, data analyses and article.

Dr. Anne de la Croix provided feedback to interview protocol and article.

Prof. Dr. Carlo Schuengel co-constructed the research protocol and collaborated in writing the main body of text for submission and revision of the article.

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