

Supplementary Material

Interview Description

Part 1 consisted of questions about the person to get to know the interviewee and their current living environment, their job, daily activities or volunteering work, their relational status, their social interactions and quality of relationship with the care professionals, and their thoughts and feelings about what having disabilities means to them.

Part 2 included questions about 'data' and 'information'. This part tested the initial level of knowledge of the interviewees about this theme, and if necessary, researchers (interviewers) could explain the terms before the interview was continued.

Part 3 of the interview was concerned with 'research' and 'data use' with a focus on 'sharing' routinely collected care data. The knowledge about these themes was discussed and their opinions, beliefs, and thoughts on benefits and worries.

Part 4 included questions about 'data linkage' between different datasets (of different organisations), using similar questions investigating knowledge, opinions, benefits, and worries.

Part 5 was posed to people who got to this stage of the interview, which were the people with VI. It consisted of questions about 'follow-up in longitudinal datasets' and data linkage. This stage was about abstract concepts of not only linking different datasets but also including the concept of follow-up of linked datasets across time. As this would require a higher cognitive level it could be too demanding for some people, and this section was therefore placed at the end of the total interview.