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Health information exchange for patients with intellectual disabilities:

a general practice perspective

Abstract

Background

Inadequate health information exchange (HIE) between patients with intellectual disabilities (ID), their carers, and GPs may lead to ineffective treatment and poor treatment compliance. Factors influencing HIE are largely unexplored in previous research.

Aim

To provide insight into the perceived HIE facilitators of GPs and general practice assistants, and the barriers in GP consultations for patients with ID.

Design and setting

An interview-based study with GPs (*n* = 19) and general practice assistants (*n* = 11) in the Netherlands.

Method

Semi-structured interviews were conducted on topics relating to stages during and around GP consultation. Transcripts were coded and analysed using framework analysis.

Results

The main themes were impaired medical history taking and clinical decision making, and fragile patient follow-up. Factors negatively influencing HIE related to patient communication skills and professional carers' actions in preparing the consultation and in collecting, recording, and sharing information. HIE barriers resulted in risk of delay in diagnosis and treatment, misdiagnosis, unnecessary tests, and ineffective treatment regimens. HIE facilitators were described in terms of GP adjustments in communication, planning of consultations, and efforts to compensate for fragile follow-up situations.

Conclusion

Inadequate HIE should be seen as a chain of events leading to less effective consultations, substandard treatment, and insufficient patient follow-up. The results indicate a mismatch between GPs' expectations about professional carers' competencies, responsibilities, and roles in HIE and the setting in which professional carers operate. Further research should focus on how daily GP practice can be attuned to the practicalities of HIE with patients with ID and their professional carers.

Keywords

continuity of patient care; general practice; health communication; health information exchange/management; intellectual disability.

INTRODUCTION

In general practice care, adequate health information exchange (HIE) is fundamental to diagnosing and treating health problems.[1–4] HIE, which can be defined as the exchange of oral or written patient health information among doctor, patient, and others involved, may include facts about, or perceptions and observations of, symptoms or treatments.[5,6]

Regarding patients with intellectual disabilities (ID), HIE can prove problematic. Many people with ID have difficulties exchanging health information with carers and health professionals.[7,8] Additional clinician-related and healthcare-system-related factors further impair healthcare provision to this group,[9,10] resulting in considerably poorer health for them than for people without ID.[11–13] Calls are often made to improve the quality of health care and reduce the increased rate of premature deaths in this population.[14–16] A HIE perspective may offer opportunities to clarify and counter the mechanisms behind inadequate healthcare access and healthcare provision for people with ID.

GPs face many HIE-related problems when caring for patients with ID. Impaired doctor–patient communication may easily lead to absence of diagnostic information, in addition to difficulties relating to inaccessible or incomplete medical histories and complicated retrieval of health information from several informants in fragmented disability support systems.[5,15,17] Given the negative influence of these problems on the effectiveness of GP care for people with ID, there is reason to study HIE for this GP patient group.

Previous research has focused mainly on doctor–patient communication during consultations and GPs' educational needs and roles in providing medical care to people with ID, without specific emphasis on HIE outside the consultation or GPs' experiences with HIE.[18–20] This study aimed to investigate the GP perspective on HIE processes and that of GP assistants (GPAs). In the Dutch primary care system, GPAs have important roles in triage decisions during receptionist activities and in channelling health information to the actual consultation. In addition, they perform certain medical-technical tasks and their role thus resembles the work of practice nurses in the UK more than the work of UK receptionists.[21,22] The research question in this study is: 'What are the experiences of GPs and GPAs with facilitators and barriers in exchanging health information of patients with ID during and around consultation?'

METHOD

Participants

Semi-structured interviews with 15 GPs and 11 GPAs and one group interview with four GPs were conducted. Participants were recruited between June 2012 and December 2013 using the network contacts of the

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Submitted: 17 February 2016; **Editor's response:** 6 April 2016; **final acceptance:** 9 May 2016.

This is the full-length article (published online 2 Aug 2016) of an abridged version published in print. Cite this version as: **Br J Gen Pract 2016; DOI: 10.3399/bjgp16X686593**

How this fits in

Patients with intellectual disabilities experience poorer health than the general patient population. A health information exchange perspective can help to counter this health disparity. This study identifies a mismatch between GPs' expectations of professional carers and the practice of exchanging patient health information. Such insight could be used to better attune GP care to the specific care setting of patients with ID.

Primary and Community Care department (Radboudumc) and the Dutch Association of Intellectual Disability physicians. GPs were purposively sampled regarding their estimated number of patients with ID, GPs' sex, and urbanisation level of the practice location (Table 1). GP participants were contacted by phone or e-mail and provided with oral and written information. Four contacted GPs declined to participate because of time constraints. One GP specifically asked for a group interview and recruited three GPs working in the same region, because they wanted to share their opinions on the subject. In eight of the 19 GP practices, a GPA could not be interviewed for logistical reasons. Written informed consent was obtained before participation, and a book was offered in appreciation of GPs' efforts.

Table 1. Characteristics of participating GPs ($n = 19$) and GP assistants ($n = 11$)

Patients with intellectual disability per GP practice,[a] *N*	
Median	60
Mean	71
Mode	80
Range	10–380
Sex,[b] *n* (%)	
GPs	
Male	12 (63)
Female	7 (37)
GP assistants	
Male	0 (0)
Female	11 (100)
Urbanisation GP practices,[c] *n* (%)	
Rural area	6 (32)
Urbanised rural area	10 (53)
Urban area	3 (16)

[a]Reference data of Dutch GP practices (data from 87 practices): on average 10 people with ID (median 8; range 0–70) within a standard-size general practice, serving 2350 patients.[23] [b]Sex was similarly distributed among participants in the present study sample compared with the Dutch professional group of GPs.[24] [c]Percentages were rounded and therefore add up to 101%. Reference numbers for the Dutch professional group of GPs: rural area 11%; urbanised rural area 42%; and urban area 48%.[24] ID = intellectual disabilities.

Data collection and analysis

All interviews were conducted following a topic guide (Box 1) based on a preliminary literature review[5] and structured around the stages before, during, and after GP consultation. GPAs were interviewed on the topic 'Organising and preparing for a doctor's appointment'. All interviews were conducted by two trained researchers and lasted 30–60 minutes (GPs), 5–20 minutes (GPAs), and 75 minutes (GP group interview). Interviews were audiotaped with permission and transcribed. Transcripts were analysed following a framework-analysis approach (Appendix 1),[25,26] supported by ATLAS.ti software (version 7.1). Data collection proceeded until saturation during analysis was reached. Results from analysis phase 2 (Appendix 1) were summarised for reflective discussion and cross-checking with 51 field experts during an invitational conference on primary care for people with ID.[27] The COREQ criteria list for qualitative research was used to guide the analysis and the report.[28] Quotes and Box 1 were translated from Dutch by a professional translator.

RESULTS

Two overarching themes describe GPs' and GPAs' experiences with problems during and after consultation: (1) impaired medical history taking and clinical decision making, and (2) fragile patient follow-up. Perceived HIE barriers are patient related and professional carer related, interfering with the collection of sufficient patient information for the diagnostic process and the provision of sufficient GP information for adequate compliance and follow-up. HIE facilitators were described mostly in terms of GP adjustments in communication, planning of consultations, and follow-up actions (Box 2). GPs discussed their efforts to compensate for fragile follow-up situations and the consequent distribution of responsibilities.

Impaired medical history taking and clinical decision making

Retrieving and assessing information from patients. Lack of adequate health information created difficulties for GPAs in assessing the reason for the encounter and following triage protocols. GPs found it difficult to obtain information from patients on the nature and history of the medical problem, including patients' concerns and expectations. They mentioned patients' difficulty expressing nuances of complaints, reflecting on their feelings, and understanding GPs' questions and abstract concepts. Consequently, GPs often deemed

Box 1. Interview guide topics relating to stages during and around GP consultation

Topics and prompting questions

Before GP consultation

Organising and preparing for a doctor's appointment

a) How does the triage of patients with intellectual disabilities carried out by your GP assistant go compared with the triage of regular patients?[a]

b) Could you give some information about the substantive preparation for the consultation by your patients with intellectual disabilities?

During GP consultation

Doctor–patient communication and GP adjustments in communication and planning of consultations

a) What is your experience with history taking in patients with intellectual disabilities?

b) Do you make any adjustments to ensure a more effective consultation?

c) How do you assess your doctor–patient communication skills regarding this patient group?

Developing and discussing a management plan

a) Do you feel you have gained enough information at the end of a consultation to draw up a management plan?

b) How do you communicate the plan to the patient and their (professional) carers?

Roles of third parties during consultation

What is your experience with a third party such as a professional carer or a relative being present during the consultation?

After GP consultation

Sharing health information between GP practice, patient, professional carers, and relatives

After a consultation, does communication about your patients with intellectual disabilities take place between you and other people or professionals such as relatives or professional care staff?

Realisation of the management plan and receiving information on follow-up

a) What is your experience with the execution of the management plan drawn up by you?

b) What information about your patients with intellectual disabilities would you like to receive after they have consulted you? Would you like to receive information only if their symptoms persist, or also if they are feeling better?

General

GP's medical knowledge with regard to patients with ID

How do you assess your medical knowledge regarding this patient group?

Do you have any additions or other observations?

[a] *Topic in interview with GP assistants. This question was asked to both GPs and GPAs. For GPAs, this was the only question in the interview (in the version 'How does the triage of patients with intellectual disabilities go compared with the triage of regular patients?').*

patient health information unreliable, and history taking often could not be deployed fully as a diagnostic instrument:

> *'I have to make a lot of assumptions, as you can never know whether the question you ask is fully understood and the answer you get is fully reliable. So I always wonder if the information I'm getting is accurate. So you begin to doubt the reliability of the history.'* (GP 4)

According to GPs, many patients with ID could not understand explanations of the diagnosis and management plan, making it difficult to involve them in decisions about their care:

> *'It is very difficult to let them participate in decisions about possible treatments. If you offer a person with intellectual disabilities a wide range of options, he or she gets stuck. The nuances are often complex … You'd like to treat them as normally as possible, but pointing out all possibilities to them is counterproductive.'* (GP 10)

GPs considered these problems a serious risk for underdiagnosis and undertreatment. Lack of information led to sometimes unnecessary and burdensome tests or treatments, and it took GPs longer to identify medical problems and start effective treatments:

> '[You run the] *risk, of course, of becoming too defensive and running too many tests … "Well, let's take an extra blood sample, as I am not fully sure what is the matter."'* (GP 19)

Professional carers' preparatory work and support during consultation. GPs considered that the presence of family or

Box 2. Main barriers and facilitators in health information exchange

1. Impaired medical history taking and clinical decision making

Patient-related factors

Barriers

Lack of (reliable) health information for triage protocols, history taking, shared decision making, and diagnosis/treatment plan, resulting from difficulty in understanding and communicating various types of health information:

- Conveying the reason for encounter
- Conveying the nature and history of the medical problem
- Conveying concerns and expectations of the consultation
- Expressing nuances of complaints
- Reflecting on feelings and emotions
- Understanding abstract concepts (for example, time and body functioning)
- Understanding GP's questions and explanations of diagnosis and management plan

Professional-carer-related factors

Barriers

Lack of (reliable) health information with regard to patient's condition, medical history, social context, communication level, or reason for encounter; deemed related to:

- Carer staff shortages
- Lack of competencies in identifying and monitoring health problems
- Inadequate recording
- Shortcomings in supply of patient information for GP's medical records

Facilitators

- Preparing the consultation
- Attendance of (informed) carer during consultation, preferably family or regular professional carers
- Use of communication forms
- Awareness of carers' roles in providing information during the consultation

GP-related factors

Barriers

- Time constraints (hindering shared decision making in particular)

Facilitators

Adjustments in communication:

- Speaking slowly
- Adjusting language level
- Taking more time
- Putting effort into making patient feel at ease
- Using self-made drawings
- Safeguarding patient's control over the conversation

Adjustments in planning of consultations:

- Cutting management plans into smaller pieces during following consultations
- Scheduling extra consultation time
- Blocking time slots to allow professional carers to accompany
- Planning extra telephone consultations with carers absent during the consultation

Long-term relationship between GP and patient with ID helps to:

- Judge reliability of patient information
- Identify patient's concerns
- Understand patient's communication style
- Build a trusting relationship with patient

Long-term relationship between GP and professional carer helps to:

- Judge reliability of patient information

... continued

professional carers during consultation was often indispensable in providing information, although problems could occur when professional carers were not able to provide details on the reason for consultation, course of illness, or medical history. Other possible professional carers' roles, such as partners in shared decision making or clarifying GPs' words, were scarcely mentioned by GPs. Family and regular professional carers were considered better informed, but carer staff shortages often led to less informed trainees or temporary carers attending, resulting in lack of diagnostic clues:

'And then they [carers] *arrive here, not having prepared anything. Then I think "And what am I supposed to do now?! I can't do anything!" Sometimes I send them back straight away, leaving them empty handed. "But we are not here for nothing." "I know that something might be wrong, but I can't solve a problem which is not clear. I can't do anything at the moment. I do not make prescriptions based on quicksand. And I am not going to run a troublesome blood test based on a vague story."'* (GP 10)

Medical records often lacked information that GPs needed from professional carers, such as communication level, social context, and medical history. They estimated that a correct diagnosis and treatment plan could be established much more quickly if professional carers prepared adequately and were more aware of their role during the consultation. GPs were positive about the use of communication forms, on which carers, often together with patients, write down patients' complaints and questions. Some believed that this could even make the attendance of a carer redundant.

Professional carers' roles and competencies in identifying and monitoring health problems were often regarded by GPs and GPAs as being comparable with those of parents caring for their children, but these expectations often were not met in practice:

'My approach is to treat these people in the same way you treat your own children. But then they wait 3 days for the actual appointment, because of understaffing. Then I think: "This is outrageous! That patient must be seen today." You would do that if it were your own child, wouldn't you?' (GPA 1)

According to GPs and GPAs, the medical knowledge level varied considerably among professional carers, and this also made it difficult for GPs to know what to reasonably expect or demand from professional carers:

'It is important that a parent [of a child with intellectual disabilities] *gains extra*

Box 2 continued. Main barriers and facilitators in health information exchange

2. Fragile patient follow-up

Patient-related factors

Barriers

- Difficulty retaining and restating information from the consultation at home

Professional-carer-related factors

Barriers

Lack of information in carer records with regard to diagnosis and management plan; deemed related to:

- Absence of carers during the consultation
- Presence of part-time temporary care staff in the care organisation
- Lack of competencies in processing health information
- Inadequate recording and sharing between colleagues

Mismatch between GPs' and professional carers' working hours

GP-related factors

Facilitators

- Extra checking of patient's understanding
- Provision of information from the consultation in writing and by calling carers at home
- Explicit requests to professional carers to share and record information
- Reminders in electronic health records to call patients after 'no-show'
- Notifying intended recipients of professional carer information

expertise. I hope the [professional] *carers too have gained that … But sometimes they haven't. They are not required to have medical knowledge. Nevertheless, there are lots of medical aspects involved in dealing with people with intellectual disabilities. I expect carers to have that knowledge … but I don't know what demands can be made.'* (GP 13)

GP adjustments in communication and planning of consultations. GPs often compared communication with patients with ID to communication with children, with whom they also speak more slowly, adjust their language, take more time, and put extra effort into making the patient feel at ease. GPs used self-made drawings to aid patients' understanding and tried to safeguard patients' control over the conversation. This type of communication was considered one of the GPs' core competencies, although considered restricted to patients with mild to moderate ID.

Time constraints during the consultation particularly hindered the shared decision-making process. To adjust to this, GPs cut management plans into smaller pieces during several follow-up consultations and involved the attending carer, while still striving to incorporate the patient's opinion, as this GP mentioned:

'I suppose clients are used to many people making decisions for them: but that is not desirable. I think it is very important for them to take their own decisions. I always try to ask, in a way they can deal with: "What do you think about it?" But that is not at all easy.' (GP 4)

Relational continuity appeared to be a facilitating factor for adjustments in GP communication. For GPs, it was easier to identify patients' concerns, attune to individuals' communication style, and judge the reliability of patient information if patients were familiar. GPs and GPAs also felt that patients with ID, more than patients without ID, need a trusting relationship with the same doctor to be able to speak freely. Additionally, GPs profited from long-term relationships with professional carers in judging the value of carer-provided information:

'I take the phone calls of some [professional carers] *very seriously, whereas I have my doubts about the calls of other carers. After a while, you get to know each other and things get a little easier. Then you know that, when a particular carer calls about someone, you must take it seriously.'* (GP 6)

Consultation planning was adjusted to create optimal conditions for doctor–patient communication, such as scheduling extra consultation time or blocking time slots to allow professional carers to accompany patients. In addition, telephone calls were arranged with carers after consultations when not enough health information could be retrieved.

Fragile patient follow-up

Gaps in the transfer, recording, and sharing of information by patients and professional carers. GPs expressed concerns about the correct execution of treatment plans because of a lack of information available in the patient's home setting, rendering patient follow-up a fragile situation. They suspected that many patients with ID had problems retaining and restating information at home and that a considerable amount of information was lost or transformed through reliance on transfer by patients themselves:

'I always inform the patient, of course, but I wonder what information he or she will remember and tell to others. And will that be correct?!' (GP 11)

GPs often noticed that information, directly transferred by them to professional carers during or after the consultation, had not been recorded or shared with colleagues:

'For instance, something was agreed by telephone, but for one reason or another not passed on correctly ... You find out later and may think: but that was agreed on, wasn't it? ... If by chance you come there on another occasion, it may turn out that something is going wrong which you thought was going right.' (GP 3)

This led to situations where GPs' instructions for referrals or the administration of medication were missing from carer records. GPs postulated that not only the presence of part-time temporary care staff, but also a lack of carer competencies in processing health information, contributed to these problems. Some GPs were dissatisfied with professional carers' attitude and occasional responses when confronted with GPs' expectations in this respect:

'Tasks are increasingly being broken down into smaller parts, and an increasing number of people are working temporarily. That means that more and more information needs to be passed on. Actions need to be noted down, passed on, and communicated ... At locations where many part-timers work, you sometimes see that something has been badly arranged. You get the answer: "You need to ask someone else. This is my first day here, so I know nothing about it." Those things are easily loaded onto someone else. Then I think: "That is not right, you should have informed yourself about it. Why not start the day by studying the report? And inform yourself about what has happened to your clients over the course of the week?"' (GP 7)

GP adjustments to secure information transfer and patient follow-up: a trade-off of responsibilities. In regard to compensating for fragile follow-up circumstances, responsibility emerged as an important topic. GPs ascribed responsibility to attending professional carers for recording health information from the consultation. The more important the information for the patient's wellbeing, however, the more GPs felt responsible and took action to ensure that relevant information was recorded in client records:

'If I put things down in writing, or ask specifically: "Please arrange that with your colleague as well?" ... so that I know it is put on the file in a proper way, that offers a greater chance of success. Nevertheless, there is no guarantee that it is put on their file correctly.' (GP 13)

GPs put extra effort into checking understanding in patients with ID and tried to inform professional carers or family at home, so that they could provide further explanation to patients. They often encountered problems in contacting professional carers, however, because of a mismatch between GPs' and carers' working hours:

'Then I ask the assistant: "Please make sure the carer directly involved is contacted and calls me back?" And then it usually takes 3 days to reach the person in question.' (GP 8)

Sharing diagnosis and treatment information with professional carers created a shared responsibility for realising the treatment, according to GPs:

'That [filling in a transfer form] *means putting it down in writing and ... that enables someone to show it to his or her carer, so that person too is informed. As a result, it becomes a shared responsibility, so to speak.'* (GP 2)

GPs considered patients with ID and their carers jointly responsible for monitoring patients' health and for initiating feedback on the course of treatment. If they felt that problems could occur in carrying out the treatment, GPs took extra measures to guarantee effective execution. They, for example, put reminders in their medical records to call patients should they miss an appointment. Others tried to guarantee transfer of referral information by professional carers by notifying the intended recipients:

'As a result, we ... have in the meantime what you might call a shadow consultation by sending an e-mail that says: "Please note that the carers should pass on this question to you."' (GP 8)

GPs considered these types of adjustments partly their responsibility, but to a great extent also felt uncomfortable with the extra demands on effort and time.

DISCUSSION

Summary

This study aimed to provide insight into GPs' and GPAs' perceived HIE facilitators and barriers during and around GP consultations for patients with ID. Analysis resulted in two overarching themes — (1) impaired medical history taking and clinical decision making, and (2) fragile patient follow-up

— and revealed barriers in the forms of problematic patient communication skills, inadequate collection of information and preparation by professional carers prior to the consultation, and gaps in recording and sharing information by carers afterwards. This resulted in risk of delay in diagnosis and treatment, misdiagnosis, unnecessary tests, and inadequate implementation of treatment regimens. GP adjustments to communication and consultation planning, and continuity of GP and carers, facilitated HIE. A specific consideration of GPs concerned the distribution of HIE responsibilities among GPs, patients, and professional carers.

Strengths and limitations

Strong elements of this study are the inclusion of both GPs' and GPAs' perspectives and the focus on the stages during and around consultation, elucidating the chain of events leading to qualitatively less effective consultations, treatment, and patient follow-up.

The exploratory nature did not permit a complete analysis of contextual factors that could influence HIE, and data gathering was limited to interviews. However, cross-checking with field experts helped deepen the contextual understanding of these results.

Bias could have occurred by including GPs with a considerable number of patients with ID, who were possibly relatively experienced with ID patient communication and necessary adjustments to match patients' needs. Nonetheless, this was also needed to reveal a full range of GP adjustments applied and considered important in practice.

Comparison with existing literature

Two other studies touched on aspects consistent with the present findings: difficulty of patients with ID recounting medical information and lack of documentation by professional carers, making GPs more cautious about the validity of their diagnosis.[17,29] In other ID literature, doctor–patient communication problems were described broadly as interfering in medical assessment and treatment,[5,30,31] but concrete effects on the process or outcomes of consultations from a GP perspective remained largely unexplored.

Lack of GP competencies and training in communicating with patients with ID is often regarded as an issue by patients, carers, and GPs.[17,31–35] In the present study, however, GPs considered communication with patients with mild to moderate ID to be one of their core competencies, and training needs were not mentioned in this respect.

Obtaining high-quality information appeared to be a key objective for the GPs in this study. Correspondingly, they displayed a predominantly task-oriented approach in consultation, and patient-oriented communication was also recognised to be beneficial for information gathering.[36,37] For GPs, for example, attuning their communication style to an individual patient's needs facilitated retrieval of relevant patient information. In this respect, it is remarkable that professional carers were talked about primarily by GPs as carriers of information and not as facilitators of GP–patient communication. The suggestion made by some GPs that communication forms may compensate for carers' absence can be similarly regarded. However, carers can also help patients with ID to express their own perspective and can support GPs in communicating in the best way,[38,39] and in this way they are of twofold importance for HIE.

Implications for research and practice

From the present results it is apparent that, from the GP perspective, HIE problems come down to 'necessary information not arriving at the consultation' and 'loss of important consultation information afterwards'. Deploying HIE tools, such as communication forms or audiotaping the consultation, together with other GP adjustments, may help overcome commonly occurring HIE barriers. However, this alone is insufficient to secure adequate HIE. The present results raise questions about the extent to which GPs' responsibility for following up on their patients can be shared with professional carers. Therefore it is recommended to check expectations with regard to professional carers' competencies in monitoring patients with ID and their roles during the GP consultation. It is equally important to clarify the distribution of responsibility for exchanging health information and for acting on this information.[40]

On the basis of the present study and earlier research on the perspectives of patients with ID, professional carers, and relatives,[41] the next research step could be to focus on how to attune daily GP practice to the practicalities of HIE with patients with ID and their professional carers. Prioritising the most important procedural steps in HIE with these groups, and, moreover, clarifying which steps are best influenced by whom, can help to find the best practical solutions to overcome HIE barriers.

Funding

This study was funded by a grant from the Netherlands Organisation for Health Research and Development (ZonMw; grant number 154012224), Centraal Ziekenfonds groep (health insurance company fund; grant number AFVV 11-043) and research consortium Stronger on Your Own Feet (Sterker op Eigen Benen). The funders had no role in designing this study, collecting, analysing, or interpreting the data, or in writing the report.

Ethical approval

The study protocol was reviewed by a research ethics committee (CMO Region Arnhem — Nijmegen, the Netherlands, registration number 2011/409).

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors thank the GPs and GP assistants who participated in this study for their contribution.

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Appendix 1. Sequential framework-analysis phases in this study

Phase	Action	Result
1. Creating and applying an analytical framework	Assigning fragments of transcripts to codes, organising codes into categories, and recoding transcripts	An analytical framework structure for the data, structured into the stages before, during, and after the GP consultation
2. Constructing a framework matrix	Mapping (summarised) parts and quotes of individual transcripts per category in a cross table sheet for both GPs and GP assistants. This allowed for intra- and inter-participant comparisons and identification of associations between preliminary themes	A selection of relevant categories and preliminary themes, summarised for reflective discussion within expert panels
3. Reflective discussion of categories and preliminary themes with expert panels	Categories and preliminary themes were discussed and commented on by expert panels during an invitational conference on primary care for people with intellectual disability	Refining of arising themes and mapped associations between themes
4. Constructing a narrative summary	Converting the framework matrix and comments from the expert panels into a narrative summary, combining the experiences of GPs and GP assistants	A comprehensive report with mapped connections between categories and themes
5. Interpreting and deriving themes relating to health information exchange barriers and facilitators	Comparison and critical discussion of themes, barriers, and facilitators in relation to health information exchange	Two major themes and a list of barriers to, and facilitators of, health information exchange