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Use of a Data-Sharing System During Diabetes Consultations

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Abstract. Patient-gathered self-management data and shared decision-making are touted as the answer to improving an individual's health situation as well as collaboration between patients and their providers leading to more effective treatment plans. However, there is a gap between this ideal and reality – a lack of data-sharing technology. Here, we present the impact that the FullFlow System for sharing patient-gathered data during diabetes consultations, had on the patient-provider relationship and consultation discussion.

Keywords. Digital health, Data-sharing, Diabetes, Pragmatic trial, mHealth

1. Introduction

Access to healthcare has become more dependent upon technology. Whether it be the use of apps and social media support groups to aid in health self-management, or use of an online appointment system for consultations, digital technologies aid in the flow of health services and information. However, the collaboration between individuals using apps and healthcare providers (HCPs) in formal consultations is underutilized. This is largely because of the lack of solutions that can securely share data from an app and present it in a mutually understandable way that addresses both patients' and HCPs' treatment priorities.

We conducted a 6-month pragmatic mixed-methods study to test the feasibility of using a data sharing system during diabetes consultations. The overall project *The Full Flow of Health Data Between Patients and Healthcare Systems* (FullFlow project) was funded by The Research Council of Norway (Forskningsrådet) (ref. 247974/O70). In this paper, we present results of the feasibility of using such a system between HCPs and patients, and associated patient-provider relationship during consultations.

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2. Methods

The FullFlow feasibility study, allowed for the real-world implementation of a system for sharing patient-gathered data during diabetes consultations. The FullFlow System, as it will hereby be referred to, includes the Diabetes Diary app (DD app) for patients as well as an online display of raw and analyzed data from the app, for use during consultations discussions between an HCP and patient (the FullFlow Display) [1]. Details of the design of the system [2] and the study protocol [3] have been published elsewhere. Briefly, recruitment included contacting HCP offices, and presenting the whole FullFlow System, followed by a brief pre-study survey of their perceptions. Interested HCPs recruited patients with Type 1 (T1D) and Type 2 Diabetes (T2D). After informed consent was collected, patients were instructed to download the DD app [4]. The intervention encouraged them to gather data about their diabetes self-management via the DD app on their smartphone. Patients were instructed to schedule at least one consultation at the end of the 6-month period, with the option to schedule more during the 6-months if they wished. Patients then chose which data to share with their HCPs during diabetes consultation(s) and discussed the data using the FullFlow Display. Following the consultation, patients completed a study-end questionnaire about their use of the DD app, the consultation discussion, and use of the FullFlow Display. After the consultation, HCPs reported their own experiences with the FullFlow Display and patient clinical measures via the post-consultation survey. A study-end focus group was arranged for patients to discuss their experiences, which was audio recorded and transcribed.

We were able to remotely coordinate all study tasks using an online study-administration system [5]. This system also enabled us to allow participants to answer questionnaires remotely via the DD app, as well as automatically collect data from the DD app, and send reminders to schedule a consultation with their HCP.

While data were collected about 1) the participant's self-management and use of the DD app, 2) consultation discussion and 3) use of the FullFlow Display during consultations [3], this paper will report analysis of the second and third topics as they relate to feasibility and patient-provider relationship. Feasibility was assessed via results related to use and perceptions of the system. Patient-provider relationship was assessed using which information was discussed, and HCPs' understanding of patients' situations.

This project was found exempt by the Regional Committees for Medical and Health Research Ethics for Northern Norway (ref. 2018/719) and then approved by the University Hospital of North Norway's Personal Data Protection Officer (project nr. 02080, ref. 2018/4027).

3. Results

Of the 26 HCP offices contacted, 11 offices invited us to present the FullFlow System, n=17 HCPs answered the pre-study survey and n=6 agreed to participate and recruit patients (P1-P8). Eight patients (n=4 with T1D, n=4 with T2D) were enrolled. Electronic informed consent forms were completed online and collected via the study-administration system. All individuals completed the first questionnaire set (Q1), n=7 patients completed the second questionnaire set (Q2), and n=4 (n=1 T1D, n=3 T2D) participated in the study end focus group meeting. Three of the recruited HCPs were able to recruit patients and held consultations. This study was about the use of the system by

HCPs and participants together. Therefore, results are presented as responses to topics of questions by pairs of HCPs and the participants they saw during each consultation during the study. This was done for ease of comparing HCP and participant perceptions of usage and consultation discussion, as we intended to honor the intention of the study.

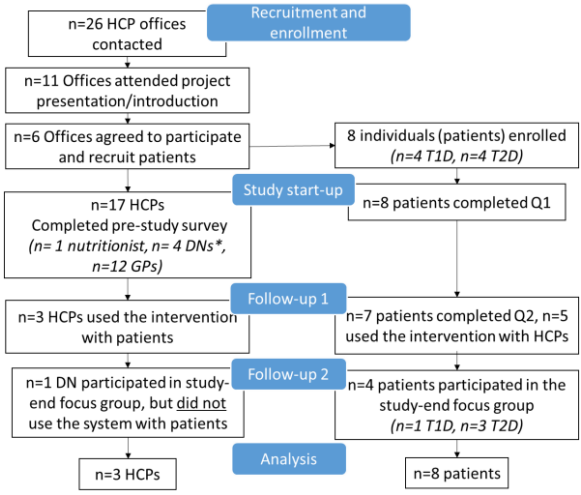

Figure 1. Study flow diagram

HCPs' first impressions of the FullFlow System included that this solution would be effective for patients who lived remotely. A diabetes nurse (DN) noted that its effectiveness was "dependent upon the patient logging [and sharing] enough data". One of the general practitioners (GPs) believed that "it can be motivational for the doctor and patient", while another GP wanted this system to be compatible with the patient journal system. They suggested that information about changes in a patient's self-management and health be "journal-note friendly". Unfortunately, it was not possible to track which of the HCPs from the pre-study survey participated in the study.

After each consultation patient and HCP participants included responses - in the HCP post-consultation survey and patient post-study questionnaire - about which FullFlow Display features they recall using (Table 1) and how useful it was to them and their consultation discussion from the HCP (Table 2) and patient (Table 3) perspectives.

Table 1. Participant and provider responses about which useful features of the FullFlow Display they recall using during the consultations *(results only presented for HCPs and participant pairs that both answered)*

Questions	HCP1	P4	HCP1*	P7*	HCP2	P5	HCP3	P8
Overview	x	x	x,x		x	x	x	x
Identified adverse events	x						x	
Detailed views	x	x				x	x	
All data in one graph	x		x,	x				
Period view	x	x			x		x	
24-hour view	x	x					x	
Sum over time	x		x,x	x	x			

*HCP1 and P7 met for two consultations during the study. Therefore, results are presented as [response for visit 1, response for visit 2]

While P1 did not respond, HCP1 recalls using the following features: *Overview screen* (including a summary of which patient-data was shared), *Period view screen* (a screen showing each data type in separate graphs, between selected dates), and *Sum over time* (sum of each data type, for the whole time period available). While P6's HCP did

not respond, P6 recalled using the *Overview screen*, *Identified adverse events* (for example, hypoglycemic events identified in the shared data, and presented in the *Overview screen*), and *Detailed views screen* (list of all values, dates, and comments per each type of data shared) features of the system during their consultation. P2 reported that none of the features were useful to them.

During the study-end focus group meeting, P8 reported that despite "some technical difficulties in the beginning", their GP was,

"very clever with the presentation of the data… we saw ups and downs in the blood glucose, and he asked what I had eaten that day at that time…. We are going to do exactly the same the next time…If possible, outside of the project" (P8)

Similarly, P4 reported that "The HCP had some technical difficulties with finding the different presentations, but when we managed to open it, it was very good". In fact, it was "very useful…we saw trends and suggestions for improvement" (P4).

Table 2. HCPs' responses about use of the system, by which participant they held the consultation with.

	HCP1			HCP2	HCP3
	P1	**P4**	**P7***	**P5**	**P8**
Was the information in the system useful to you? (1-5)	3	4	2,2	5	5
The extent to which the system presented information helped to provide the patient specific recommendations (1-5)	3	4	2.2	4	5
Do you have concerns about using the system? (Y/N)	Yes	Yes	Yes	Yes	Yes
Use of the system gave me a better understanding of the patient situation (Y/N)	Yes		No, Yes	Yes	Yes
What did you and the patient discuss during the consultation?					
• Personal goals	x			x	
• HbA1c	x	x	x, x	x	x
• Blood glucose (BG)	x		x, x	x	x
• Medicine use	x	x	x, x	x	
• Diet	x		x, x	x	x
• Physical activity	x	x	,x	x	x
• Identified adverse events	x			x	

*HCP1 and P7 met for two consultations during the study. Therefore, results are presented as [response for visit 1, response for visit 2]

Most who participated in the study-end focus group agreed that the information presented by the system was relevant. One reported that the "diagrams and graphs are very difficult to read" (P6).

Participants discussed what they expected from the consultation discussions and what happened during them. P7 mentioned that they expected to "get advice about medication, diet and lifestyle. I got that, and if they were bad or good, I have to consider now after the consultation". P8 similarly expected "that my doctor got a better picture about what is happening, especially over time" and, in response, their HCP "asked me why my BG was so high, especially in the morning, and was wondering what I had eaten."

While all three of the HCPs reported having concerns about the system, P6 and P8 did not recall having any concerns. P7 acknowledged that "there is an issue with the confidence that this data is preserved and not shared", however, they were personally not concerned with using the FullFlow System during this study.

Table 3. Participants' responses about the consultation with their HCPs

Questions	**P4**	**P5**	**P6**	**P7**	**P8**
Did you and your HCP plan what to do until the next consultation? (y/n)	Yes	No	Yes	Yes	Yes

Were the recommendations of your HCP helpful to you after this consultation? (Y/N)	Yes	Yes	Yes	Yes	Yes
Do you think the recommendations you received are achievable? (Y/N)	Yes	Yes	Yes	Yes	Yes

During the study-end focus group, P4 reported discussing,

"the graphs from back in time. We talked about specific cases where the blood glucose was especially high or low, why it was like that and what I had eaten. Then I could open the app on my phone and see what I had eaten at that time. We sat together and looked at the screen and could discuss what had happened".

When asked if using the system made it easier for them to describe their situation to the HCP, P4 noted that "It is, of course, easier when you have it on a screen in front of you, compared to not having anything at all to relate to". Changes in treatment and self-management plans were also affected. "It was a little easier because we could look at specific cases and potentials/suggestions for improvement…my doctor was very realistic and gave me easy advice about diet" (P8). P7 reported receiving "advice about how I could change my lifestyle" and "feedback regarding diet. I am going to try to eat more regular meals and not that many in-between-meals". This patient also noted that the ability to "see the data visualized as graphs was very important for drawing the conclusion that I had to be medicated". P4 reported that they not only received advice for a change in medication but also a better understanding of their disease. This patient recalled that their HCP suggested to,

"take insulin before or during the meal, instead of after the meal. Now I am trying to do that. They looked at the graphs and saw that every time I had eaten my BG went up, and then down again. If I set insulin before I eat, I will get a more stable BG" (P4)

P6 and P8 experienced little or no change in treatment or self-management plans.

4. Discussion and Conclusions

The patient and HCP responses gave a comprehensive representation of how the system was used. Focus-group transcripts were consistent with questionnaire responses and contextualized how use of the system's functionalities affected their relationship and consultation discussions. It was reported that use of the system allowed HCPs to provide tailored recommendations and enable the patients to better understand how their habits affect their diabetes. In the next round of analysis, we will incorporate results related to patients' use of the DD app for self-management and how this affected and was affected by use of the system during consultations and patient-provider relationships.

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