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Clinical Letters to Patients with Intellectual Disabilities After Psychiatry Review: A Quality Improvement Project.

Short running title: Letters to patients after psychiatry review

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Aim: This Quality Improvement Project sought to improve communication between patients with intellectual disabilities and their psychiatrists by sharing medical information using an easy read letter format following psychiatric review.

Background: Writing directly to patients is in keeping with good medical practice. Previous studies have shown patients with intellectual disabilities prefer letters tailored to meet their needs.

Method: An easy read letter was used by 9 psychiatrists who handed them to 100 consecutive patients after review. Feedback of acceptability to patients was obtained using a 3-item facial rating scale and the use of free text. Feedback of acceptability was obtained from participating psychiatrists.

Results: Patients found the easy read letter helpful and felt it should be used routinely. Psychiatrists felt this approach was beneficial as well as aiding patient understanding of review.

Conclusions: The easy read letter improved communication following psychiatric review. Whereas limitations are acknowledged the authors still conclude that an easy read letter should be adopted as routine practise following psychiatric review, for people with intellectual disabilities.

Clinical letters to patients with intellectual disabilities after psychiatry review: A Quality Improvement Project

BACKGROUND

In accordance with the National Health Service (NHS) Constitution (2021), patients in the United Kingdom have a right to be involved in planning and making decisions about their health and care with their care providers. They also have a right to be given information and support to enable them to do this, and where appropriate, this right extends to their family and carers. Additionally, since the publication of the NHS Plan patients have the right to be copied into letters written about them from one health professional to another (Department of Health, 2000). The overriding objectives of such rights was to improve communication with patients, and to enable them to participate in their care. Nevertheless, current clinical practice in the UK is for hospital doctors to write letters to patients' General Practitioners (GPs) following an outpatient consultation, and for patients to receive a copy of this.

The Equality Act 2010 placed a legal duty on all service providers to take steps or make "*reasonable adjustments*" to avoid placing a disabled person at a substantial disadvantage when compared to persons who are not disabled. This Act is explicit in its requirement for including the provision of information in "*an accessible format*" as a '*reasonable step*' to be taken. Furthermore, all organizations' that provide NHS care and, or, publicly funded adult social care are legally required to follow the Accessible Information Standard, which came into force in 2016. This standard sets out a specific, and consistent approach to meeting the information and communication support needs of patients, service users, carers and parents with disabilities, impairment, or sensory loss. This standard places a statutory obligation on organizations to ensure people receive information in accessible formats, which they are able comprehend (NHS, 2016).

Additionally, the General Medical Council, the professional body and regulator for doctors, in its *Good Medical Practice* guidance for doctors advises medical practitioners, that they must give patients information they want, or need to know, in a way that they can understand (General Medical Council, 2021). To assist doctors, in this respect, the Academy of Medical Royal Colleges (AoMRC) has published guidance to ensure they meet this

requirement. This guidance encourages doctors to write their outpatient clinic letters directly to patients rather than simply copying them into letters to the patients GP, and to use understandable terminology rather than complex medical jargon (Academy of Royal Medical Colleges, 2018).

Studies have shown that professionals working in intellectual disability services, believe that a simplified version of the letter sent to the GP, following psychiatric review, should be given to patients with intellectual disabilities making it more meaningful for this patient group (Sawhney, *et al.*, 2007). It is also suggested that patients with intellectual disabilities have shown a preference to receive a separate simple letter in a large font (Sawhney, *et al.*, 2007) from their Psychiatrist. This study also suggested that patients with intellectual disabilities indicated that they tend to forget what is discussed in a psychiatric review and felt their understanding of mental illness would be increased by receiving letters given to them directly.

AIMS

This QIPⁱ describes a simple, yet innovative QIP *reasonable adjustment* to current clinical medical practice to ensure patients were written to directly in an accessible format by their psychiatrists after review. The aims of the project were twofold. Firstly, it sought to ascertain views, experience and acceptability to people with intellectual disabilities and their carers as to use of a review letter presented in an accessible format, and secondly to seek the views of, and acceptability to the participating psychiatrists about writing to patients using such an approach.

PARTICIPANTS and SETTING

A purposeful non - probability sample of patients, (N = 61 male, 39 females, with a mean age 42), were consecutively recruited into this QIP until 100 was reached; this being the agreed number for the QIP. Recruitment was undertaken across the caseloads of the 9 participating psychiatrists. Of the patients participating N = 35 had mild, 38 moderate, and 27 severe intellectual disabilities. All patients had one or more mental illness and, or epilepsy as a co-morbidity to their intellectual disabilities. They presented with: Mood Disorder N = 34, Psychosis (Schizophrenia and /Schizoaffective Disorder) N = 7,

Neurodevelopmental Disorders N = 35, Epilepsy N= 48 and Anxiety Disorder N = 14. All patients were prescribed psychotropic and, or anti-epileptic medication. They were prescribed several medicines: Antipsychotic N = 50, Antidepressants N = 28, Antiepileptic N = 64, Stimulants N = 3 and Mood stabilizers N = 4. All participants, patients and psychiatrists originated from two counties in England, Hertfordshire and Essex, over a period of three months.

ETHICS

The Hertfordshire Partnership University NHS Foundation Trust ethics committee classified this QIP as a service evaluation, and as such, its remit fell outside the governance arrangements of NHS research committees; nonetheless, permission was granted for the QIP to be undertaken. Regardless of governance arrangements, this project was conducted within the general ethical conventions of social research (Haber, 1998), and was always conducted in a manner which respected the people who participated in the process being concerned for their dignity and welfare, as set out in the Research Governance Framework for Health and Social Care (DH, 2005).

METHOD

A standard '*easy read*' clinic letter template was developed through co-design by clinicians with input from experts by experience comprising families, carers and people with intellectual disabilities. Self-explanatory pictures and symbols that depicted different facets of health and care were incorporated into the letter to facilitate understanding by people with intellectual disabilities. The easy read letter was then handed to each patient/carer at the end of their appointment, at either their outpatient clinic appointment or domiciliary visit, following psychiatric review.

The easy read letter began with an introduction by the doctor (with photograph) who undertook the review, and it then incorporated several separate subheadings which covered; mental health, physical health, current medication (and the benefits and side effects if any) and changes to, medication. It also included epilepsy, risks (risks to self and to others), vulnerability, behaviours of concern and day-to-day activities, and finally a heading about a plan which was formulated at the end of the consultation (see figure 1). This

proforma did not replace the routine clinical letter which was sent to the GP following the existing protocol.

INSERT FIGURE 1 ABOUT HERE

A second 'easy read' facial recognition form was designed to ascertain their satisfaction, or otherwise, of the format. In addition, free text boxes were also provided to capture the views and experiences of patients receiving such letters. Patients and, or carers were asked to rate the letter using a 3-point Likert scale – Green for 'helpful', Amber for 'not sure' and Red for 'not helpful'; the use of such scales and in novel ways is now common practice in health-related research such as: medicine, nursing and psychology (McLeod, 2019). They were then asked if they found the format of the letter helpful, or not, and were asked to give reasons for their answers in the text boxes provided (see figure 2).

INSERT FIGURE 2 ABOUT HERE

Additionally, feedback was sought and obtained from the psychiatrists participating in the QIP regarding their experience and the acceptability of incorporating the easy read template in their psychiatric clinics. Post clinic all data sources from both patients and psychiatrists were collected and analyzed from by members of the QIP team.

FINDINGS

There was a unanimous positive response from all patients; 100% of respondents indicated that they found the easy read letter helpful. Whereas not all patients or carers could, or chose to, provide written comments on why they found the letter helpful, they all ticked the green 'smiley' face, indicating a positive experience. There were no negative comments from patients or carers regarding their experience. Some of the free text comments that were provided identified why they found the format of this easy read letter helpful:

'good reminder on how the appointment went', reminder of 'what was discussed', 'easy to read, easier to understand with pictures', 'improved understanding', 'breakdown of headings made it easy', 'clear and concise information', 'helped staff supporting remember what happened in the appointment', 'good reflection of what was discussed'.

The feedback received from the 9 psychiatrists involved in this QIP indicated they felt it improved patient understanding, and thereby improved the therapeutic relationship between themselves as clinician and their patients. Other comments received included its potential to:

'empower patients, become engaged in their care, and 'enable them to make decisions about their treatment plans' as well as 'leading to greater patient satisfaction'.

However, concerns were raised by some clinicians regarding it as being a time-consuming exercise which could impact on their workload.

DISCUSSION

Outpatient correspondence to GPs are probably the most frequently written letters in the NHS in the UK. The clinic letter communicates the clinical information and management plans of a patient to their GP. Additionally, it serves to form part of a patient's clinical record and is an important reference point as to what was discussed. Furthermore, patients can alert the clinicians of any errors and, or update them to changes made to their treatment plan by other clinicians, thus enabling more co-ordinated care.

Within the UK, current clinical practice generally is for hospital doctors to write such letters to a patients' GP following an outpatient consultation, and for these patients to receive a copy of the letter. However, new guidance now advises doctors to write directly to patients (Academy of Royal Medical Colleges, 2018). And where doctors have adopted the practice of writing directly to patients, evidence suggest that the communication style becomes more *'patient centred'* (Logan, *et al.*, 2019). Studies have also shown that GPs are supportive of the practice of writing directly to patients, as it improves understanding of their patients resulting in GPs spending less time interpreting meaning of the content to patients (Academy of Royal Medical Colleges, 2018). The benefits of writing directly to patients is now established in various studies, and in different branches of medicine for the wider population (Logan, *et al.*, 2019; Lonergan, *et al.*, 2019). Most importantly, studies show that patients find such letters useful, supportive, and informative, and this is in keeping with the findings of this project. Studies have also revealed that patients find such letters an aide memoire of what was discussed during their consultation – complex issues

can be easily forgotten (Academy of Royal Medical Colleges, 2018). This latter point is particularly relevant for people with intellectual disabilities who may be more likely to forget due to their cognitive impairments. Finally, some studies have demonstrated that once patients who received such letters directly wished for this practice to be continued (Baker & Eash, *et al.*, 2002).

However, there seems to be less agreement around the comprehension of the content of the letters (Roberts and Partridge, 2006). In this QIP the review letter was developed as an easy read template to promote comprehension for these patients. To make it meaningful it is paramount that both the language and information is pitched to their level of development. This might require the incorporation of adaptations such as use of pictures or diagrams to facilitate better understanding as was undertaken in this QIP. It is suggested that it is an imperative for clinicians to communicate directly with the people with intellectual disability, although such correspondence to the patient is not intended to replace the clinic outcome letter routinely forwarded to the GP and other professionals involved in the care of the patient.

Whereas there is merit in the concerns expressed by these psychiatrists that their workload could potentially increase by sending such letters patients it is suggested that over time doctors would get used to and accommodate writing to patients in this way and this would inevitably speed up the process. Moreover, and perhaps more importantly communicating effectively with patients is known to be central to being a good doctor, and such practices need to be incorporated into routine clinical practice, and now where is this more important where specialist intellectual disability services should be a beacon of exemplar practice in making reasonable adjustments. This is especially relevant as writing directly to patients, in an accessible way, rather than sending them copy of the letter sent to the GP is known to improve communication with patients with intellectual disabilities. Direct communication with people with intellectual disabilities in an accessible fashion helps to empower them and is an important move toward treating them as equal partners in a consultation. People with intellectual disabilities will have a written record of the consultation which they can share with others involved in their care, thus ensuring more coordinated care. Also, having information to hand in an accessible manner will place them in a better position to be able

to take in the information and advice given by the doctor. This is important because in enabling people with intellectual disabilities to have more control of their lives and make better choices about their health is important is dependent on them understanding the information imparted to them at such reviews. Furthermore, this practice should not be confined to medical but should and could be adopted by all professionals in specialist intellectual disability services and teams to enhance care for people with intellectual disabilities.

CONCLUSION

This quality improvement project has described the implementation of an intervention to improve the quality of letters along with the accessibility, acceptability, and value to patients with intellectual disabilities. It is concluded that specialist intellectual disability services need to ensure that psychiatric review information is imparted to patients and, where appropriate their carers, in an accessible manner. Writing to patients using an easy read template should now be incorporated and considered standard clinic practice. Such practice addresses potential shortcomings in contemporary clinical practice by addressing standards required in the Equality Act 2011, and Good Medical Practice (General Medical Council, 2021). As importantly in this QIP patient, carer and psychiatrists' feedback indicates that these letters improved overall understanding post psychiatric clinic consultations and that people with intellectual disabilities found them helpful.

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FIGURE 1 APPOINTMENT OUTCOME LETTER

<p>Name:</p> <p>Clinic Date:</p>	<p>Today we discussed....</p>
	<p>Your Doctor Today:</p>
	<p>My Mental Health</p>
	<p>My Physical Health</p>
	<p>My Current Medication</p>
	<p>Reported Side Effects</p>
	<p>Any Benefits</p>
	<p>Change of Medication</p>
	<p>Epilepsy</p>
	<p>Risk to Self</p>
	<p>Risk to Others</p>
	<p>Vulnerability</p>

	Behaviours of Concern
	Activities
	Other
	Plan

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FIGURE 2 FACIAL 3 ITEM LIKERT RATING SCALE AND FREE TEXT BOXES

Is this easy - read appointment outcome letter helpful? Tick which 'face' you feel is right? Green – Helpful: Amber – Not sure: Red – Unhelpful



If you found this letter helpful, please say why:

If you didn't find this letter helpful, please say why:

ⁱ Quality Improvement Projects are used widely in the National Health Service in the UK to introduce changes to clinical practice that might lead to better health outcomes care, and, or performance by health care professionals.