Research Article

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Journal of Genomics & Gene Study

2020
Vol. 3 ISS. 2

Pre-Genetics Clinic Resource Evaluation for Adults with Intellectual Disability: The Pre-Genetics Clinic Acid

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Citation: Huafrin Kotwal (2020) Pre-Genetics Clinic Resource Evaluation for Adults with Intellectual Disability: The Pre-Genetics Clinic Acid. Vol 3 No. 2

Received: July 14, 2020; **Accepted:** July 16, 2020; **Published:** July 31, 2020

Abstract

People with intellectual disability (PWID) consistently identify the importance of health service information that is accessible and relevant. Resources tailored to the information and support needs of PWID can facilitate inclusivity in their healthcare (including access to genomic medicine) and improve healthcare outcomes. Despite the fact that PWID are commonly referred to genetics services, there is a lack of appropriate resources to help them prepare for their appointments. We therefore aimed to evaluate the feasibility and acceptability of a booklet for PWID to read with their carers prior to their genetics appointment, to help them prepare for what they may experience. With input from Easy to Read experts and PWID who were members of the New South Wales (NSW) Council for Intellectual Disability, the information booklet "Getting ready for your visit to the genetics clinic" was produced. Australian healthcare professionals (HCP) familiar with clinical genetics services were invited to complete an anonymous online survey designed to assess perceived relevance, readability and utility of the resource. Recruitment of HCPs was pursued via affiliated clinical services and email distribution through clinical genetics organizations.

Sixty-six HCPs completed and submitted the survey. The results demonstrated that HCPs believed the booklet represented a typical clinical genetics service appointment and that the majority would provide a copy of the resource to clients and their carers. They reported that the booklet was easy to understand and entailed appropriate content and images which were presented clearly and simply. Some minor modifications were recommended and incorporated into the resource. A model of customizable booklets such as this could be transferrable across clinical genetics services and guide development of other resources for PWID. This may help to reduce healthcare disparities, improve client satisfaction and facilitate involvement of PWID in their own healthcare decisions.

Keywords: Intellectual disability, Easy to Read guide, Genetics Services, Inclusive research, Access, Disparities.

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People with intellectual disability (PWID) consistently identify the importance of health service information that is accessible and relevant. Resources tailored to the information and support needs of PWID can facilitate inclusivity in their healthcare (including access to genomic medicine) and improve healthcare outcomes. Despite the fact that PWID are commonly referred to genetics services, there is a lack of appropriate resources to help them prepare for their appointments. We therefore aimed to evaluate the feasibility and acceptability of a booklet for PWID to read with their carers prior to their genetics appointment, to help them prepare for what they may experience. With input from Easy to Read experts and PWID who were members of the New South Wales (NSW) Council for Intellectual Disability, the information booklet "Getting ready for your visit to the genetics clinic" was produced. Australian healthcare professionals (HCP) familiar with clinical genetics services were invited to complete an anonymous online survey designed to assess perceived relevance, readability and utility of the resource. Recruitment of HCPs was pursued via affiliated clinical services and email distribution through clinical genetics organizations.

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Introduction

Intellectual Disability and the Health Service

Intellectual Disability (ID) is the broad term assigned to a deficit in intelligence and social ability (Scheepers et al., 2005). In a quantifiable sense, the intelligence quotient (IQ) of people with ID (PWID) falls below 70. By focusing on PWID's 'special needs,' such as the supports that they might require to participate in activities involved with typical physical and cognitive functioning (Schalock et al., 2010), many healthcare professionals (HCP) may overlook the basic needs of PWID as a patient and individual. PWID may be excluded from consultations and could have their health concerns misattributed to their disability (Ali, Scior, Ratti, Strydom, King, & Hassiotis, 2013). Such non-inclusive models of care can compromise the quality of healthcare provided to PWID and contribute to poor health outcomes, including unacceptable rates of preventable morbidity and mortality (Heslop, Blair, Fleming, Hoghton, Marriott, & Russ, 2013). A more inclusive model of care that actively involves PWID at all stages of health service development and delivery is required. Iacono and Davis (2003) assessed the impact of responding to PWID feedback on healthcare services in Australia.

They found that when hospital systems made reasonable adjustments to the priorities identified by PWID, patient outcomes were improved, including reducing unnecessary hospital visits. Ali and colleagues (2013) further demonstrated that supportive experiences for PWID can be generated when staff are more attuned to patient requirements. It is imperative that these endeavours are maintained across all types of healthcare services.

~~Tailored Informational Resources~~

When provided with the opportunity, PWID continually request information tailored to their needs (Scheepers et al., 2005; Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins,., 2006), yet

frequently these requests are not acted upon, resulting in reliance on carers to advocate for appropriate treatments and healthcare (Iacono et al., 2014). For example, Ali and colleagues (2013) found that patients were told to sign consent forms without understanding what they were consenting to. The only information booklet they received was not presented in an accessible format. There is limited literature on how to develop accessible healthcare service resources for PWID, and none that guide clinical genetics service resource development for this often-marginalized population. Rodgers and Namaganda (2005) provide some broad guidelines for healthcare services. They emphasize that in order to be effective, the needs of the target population must be established before the resource can be designed, which can be achieved by encouraging the involvement of PWID at all stages of the resource development. For example, for people with mild ID, text should have a reading age equivalent of 8 to 9- year old children, attending Australian school Grades 3-5 (Webb, 2019).

Owens (2006) describes how to translate complex concepts and information into a format that is accessible for PWID to read and understand. This format is called Easy to Read (Geukes, Bröder, & Latteck, 2019). This has served as the backbone of Easy to Read guides produced for various disability services (Scope, 2015; Inclusion Europe, 2009). The use of Easy to Read guides by non-genetic healthcare services has been shown to have a positive impact upon patient understanding of the service (Hurtado et al., 2014 and Jones et al., 2007) and reading comprehension (Fajardo et al., 2014 and Karreman, Van Der Geest, & Buursink,, 2007). Higher verbal IQs in PWID have been shown to predict better learning in an Easy to Read picture guide (Hurtado, Jones, & Burniston, ., 2014). However, Easy to Read guides assume a prerequisite level of reading ability in PWID, potentially excluding those with more severe degrees of disability (Geukes et al., 2019). Additionally, it may falsely associate verbal IQ with the capacity to gain or understand health-related knowledge, thereby under recognizing the complexity and heterogeneity of health literacy in this target population (Geukes et al., 2019).

A Need for a Pre-Genetics Clinic Aid

The increased availability of genomic sequencing, which is more likely to find an underlying molecular diagnosis for ID than previously available tests, is resulting in increased attendance at clinical genetics services by PWID (Vissers, Gilissen, & Veltman, 2016). There is therefore an increasing need for Easy to Read educational resources about clinical genetics services to enable these individuals to be involved in their health choices. Such resources may reduce PWID's reported anxiety of the 'unknown' (preparation), prompt PWID to ask questions (participation) and increase their perceived self-control (Webb, 2019). Healthcare services that recognize these important elements in providing inclusive healthcare, and make reasonable adjustments, can facilitate appropriate healthcare for PWID, which in turn may mitigate against poor hospital experiences (Iacono et al., 2014). The absence of published literature on developing accessible clinical genetics resources means that development and initial evaluation of an Easy to Read resource is worthwhile (Chinn and Homeyard 2017).

Developing a Resource "Getting Ready for Your Visit to the Genetics Clinic"

clinical geneticists and genetic counselors at a clinical genetics service in Australia identified the need for a booklet to prepare PWID with borderline or mild ID for their appointment.

Smith and colleagues (2012) and Walker and Schuler (2005) suggest recommendations for the development of patient information to ensure patients feel prepared. Preparation involves setting clear and realistic expectations of the appointment and the pathway the patient would experience (Walker and Schuler, 2005). This is a

contributing factor in mitigating patients' uncertainty, increasing their sense of preparedness and enhancing satisfaction with their care. Inadequate preparation before attending health services has been shown to have a negative

effect on patient outcomes, such as psychological distress (Forshaw, Hall, Boyes, Carey, & Martin. 2017). Reading and comprehension capabilities of PWID are largely dependent upon the individual, the extent of early intervention, level of support and education, and their exposure to early reading, (Jansche, Feng, & Huenerfauth, 2010).

This paper reports the process undertaken to develop a draft resource for PWID with the participation of PWID and Easy to Read experts and explains the findings of an evaluation undertaken with clinical genetics professionals.

Methods

The booklet content was developed in accordance with the following aims:

1. Prepare PWID for the nature/format/process of a clinical genetics session and the attending professionals they will encounter (who, what, where and when).
2. Create a template resource that other genetics services can customize and adapt to their needs.

The primary research team developing the initial draft included six genetic counselors, a clinical geneticist and a project coordinator who completed this study as a degree requirement for her Masters of Genetic Counseling.

Two PWID, members of the New South Wales Centre of Intellectual Disability (NSW CID) who provide a consultancy service, as well an Easy to Read expert from the CID, evaluated and provided feedback on initial drafts of the booklet. They recommended presenting large sections of information as separate points or lists, rather than sentence format, to enable better readability by conveying ideas concisely. They suggested to include with clear explanations relevant technical terms, such as 'clinical geneticist' and 'genetic counselor' as it was important for PWID to familiarize and understand the HCPs they would come across.

General formatting suggestions included using Sans Serif font style at size 14 consistent line spacing of 1.5 and present tense.

After six drafts, an Easy to Read, A5 foldable, 300-word booklet for PWID was developed entitled: Getting ready for your visit to the genetics clinic (Supplement 1).

The readability of the booklet was assessed using readability software titled Readable.10, which applies individual and average readability scores with utilization of the following readability formulas: Gunning Fog (Gunning, 1952), Flesch-Kinkaid (Flesch, 1948), Coleman-Liau (Coleman & Liau, 1975), Simple Measure of Gobbledygook (SMOG) (McLaughlin, 1969) and Automated Readability Index (Senter, 1967). Photographs were obtained under license from the Easy to Read photo library photosymbols.com.

Pilot Evaluation

Participants

The sample cohort was comprised of clinical geneticists and genetic counselors who were purposively recruited through an online survey invitation sent via email to Australian-based clinical genetics organizations: the Human Genetics Society of Australasia (HGSA), Australasian Society of Genetic Counselors (ASGC) and the Australasian Association of Clinical Geneticists (AACG).

Instrumentation

The survey included 23 questions, adapted from Wakefield and colleagues (2007), and collected demographic information (n=5), perceived suitability (n=8) and perceived readability and utility (n=5) of the booklet (Supplement 1).

Procedures

Study data were collected and managed using REDCap electronic data capture tools hosted at University of Sydney (Harris et al., 2019). REDCap (Research Electronic Data Capture) is a

secure, web-based software platform designed to support data capture for research studies, providing: (1) an intuitive interface for validated data capture, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages and (4) procedures for data integration and interoperability with external sources.

Data Analysis

Data analysis was performed using descriptive statistics with aid of Microsoft Excel as well as Pearson Chi-Squared Analysis via Fishers Exact Test with aid of SPSS Software (IBM Corp. Released 2012, IBM SPSS Statistics for Windows, Version 21.0, Armonk, NY: IBM Corp). For the purposes of this study, p value of <0.05 was taken as significant to identify any significant associations between perceived readability, suitability or utility of the booklet and demographic factors. Variables for each group were dichotomized. into 'yes' or 'no' responses, positive or negative feedback, length of practice of the HCP (<5 years or ≥ 6 years), age of the HCP (18- 29 years and ≥ 30 years), profession (genetic counselor or clinical geneticist) and whether the HCP had conducted an appointment with a PWID or not. Open- ended questions were included in the questionnaire to allow capture of further comments and/or suggestions.

Ethics

This study was approved by the Hunter New England Local Health District Human Research Ethics Committee (HNEHREC Reference No: 17/12/13/4.04

Results

Resource Evaluation

The booklet had an average readability score of 3.8, which is equivalent to a level appropriate for 8 to 9-year-old children attending Australian school grades 3-5. This reading ability has

been judged to be accessible for people with mild ID (Webb, 2019). In total, 66 HCPs completed the survey. It is not possible to calculate a response rate. The majority of respondents were female, aged 30 years or older (75%) and were genetic counselors (85%) (Table 1). In total, 89% of the respondents had experience with conducting an appointment with a PWID (Table 1). Different aspects of the resource evaluation are described below and supporting quotations are included in Table 2.

Table 1.Demographics of Health Care Professionals (n=66).

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Age	18-30	30-30	40-40	50-50	60-60
	15	25	13	12	1
Role	Clinical Geneticist	Genetic Counselor			
	12	21			
Years in practice	1-5 years	6-10 years	>10 years		
	27	10	29		
Appointment with PWID	Yes	No			
	59	7			

PWID – People with Intellectual Disability

Table 2. Associations between Booklet Suitability and Utility and Demographic factors.

Booklet Suitability and Utility	Group	Fisher's Exact Test p value	Supporting Quotations from HCP (n)
Booklet content was about right	Age (30 years and above)	0.018	Liked the order presented/Structure (65) Simplicity/Easy to read/Concise language (41)
HCP would give booklet to PWID before first appointment	Age (30 years and above)	0.032	Dispelling fears of the unexpected with the service (14) Promotes patient centred approach (5)
Booklet content about right	Length of practice (6 years and above)	0.022	Repetition of saying no (7) Promoting patient involvement by presenting concepts as optional (5)
Booklet has pictures of staff	genetic counselor	0.044	Like the familiarity with pictures of service, patient and staff (8)

HCP – Health Care Professionals

PWID – People with Intellectual Disability

Table 3. Health Care Professional views on (n=66) areas for improvement.

Booklet aspect	Statements about areas to improve/change (n)
	To remove
	Repetition of 'saying no to anything' needs to be reduced (4) Rewording of 'genetic counselor's role' for clarity (4) Remove 'anything' to 'you can say no to the tests' on page 10 (1)
	To add
Content	Context of appointment – why they are here (15) Explanation of genetics and its relevance to their health (9) Context of checks, questions and tests – why they are being done (6) Mention might not need to offer blood test (2) Additional information section for carers (2) Day of the week to appointment date (2) Patient can have time with the doctor without carer present (1) Carer will take client to the clinic (1) When and who will get results if testing is done (1) Photos will not be shared on the internet (1) Physical examinations are for support and not judgment (1) Feelings patient may feel with encroachment of personal space (1)
Pictures	Front cover picture not appropriate appealing (10) Blood test picture/needle may provoke anxiety/be confronting (5) Larger sized pictures (4) Waiting room picture (2) Outdated pictures (2) Higher quality pictures (1)
Personalization	Pictures of staff room may change at the last minute, cause anxiety or confusion (13) Not enough time, staff or resources to personalize booklet (10) Not practically beneficial to include client picture (6) Privacy concerns by staff with their picture (3) Provide space for client to add their picture at home (1)

Booklet Content

The majority of HCP respondents believed the content of the booklet reflected a typical clinical genetics appointment (83%, n=55/66) (Figure 1). The majority also viewed the content was in the right order (98%, n=65/66), and that the amount of images and content was about right (89%, n=59/66 and 83%, n=55/66 respectively) (Figure 2). Associations between the suitability of content and demographic factors were assessed. HCPs who are expected to be more experienced (30 years or older, and those who had been practicing for 6 years or longer) were more likely to perceive that the amount of content in the booklet was about right (Fishers Exact Test p = 0.018 and Fisher's Exact Test p = 0.022 respectively (Table 2). No other significant associations were found between booklet suitability (i.e., booklet order and content: as well as images' clarity of presentation, usefulness and number) and demographics (i.e., age, gender, whether HCP had conducted appointments with PWID, length of practice and profession).

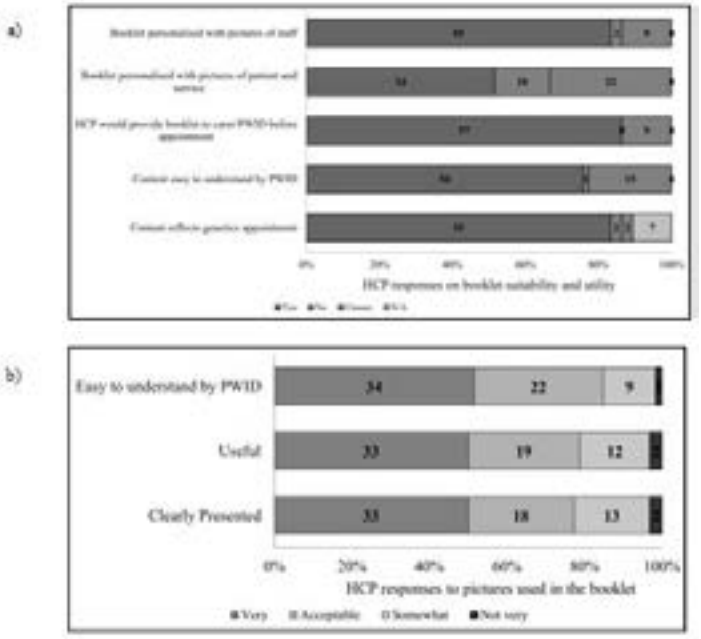

Figure 1: Health care professional views on booklet suitability, utility and readability: a) feedback on utility and readability; b) feedback on pictures used.

HCP – Health Care Professionals

PWID – People with Intellectual Disability

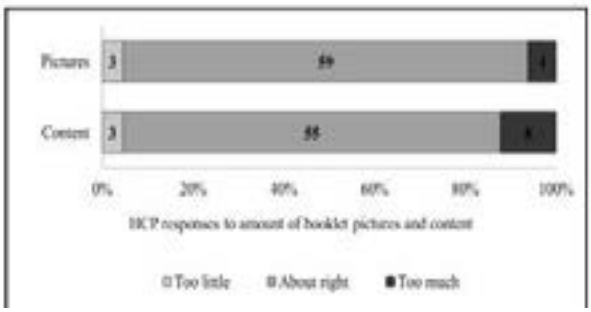

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Figure 2: Health care professionals' views on booklet content and images: a) order of content in booklet; b) booklet content and pictures.

HCP – Health Care Professionals

PWID – People with Intellectual Disability

Booklet Readability

Approximately three-quarters of respondents (76%, n=50/66) perceived that the booklet's content would be easy for PWID to understand (Figure 1). No significant associations were found between HCP demographics (i.e., age, gender, whether HCP had conducted appointments with PWID, length of practice and profession) and booklet readability (i.e.,

perceived ease of understanding for PWID).

Booklet Utility

The majority of respondents (86%, n=57/66) stated they would provide the booklet to their clients with ID and/or client's carers prior to their first appointment (Figure 1). This trend was especially apparent with the HCPs aged 30 years and older (Fisher's Exact Test p = 0.032). Additionally, genetic counselors were more likely than clinical geneticists to support customization of the booklet with inclusion of images of the staff who the patients with ID would likely see in clinic (Fisher's Exact Test p =0.044; Table 2). No other significant associations were found between demographics (i.e., age, gender, whether HCP had conducted appointments with PWID, length of practice and profession) and booklet utility.

HCP Feedback on Booklet

Feedback from respondents was organized and summarized into three major aspects: content, images and personalization (Table 3). Individual statements were grouped and summarized, and their frequencies were recorded (Table 3).

Since HCPs with greater experience viewed the amount of content in the booklet as appropriate, and the majority of HCPs reported they would provide the booklet to a client and/or carer prior to their first appointment, it is suggested that the booklet reflects a typical genetics appointment. One respondent wrote, "[I appreciate] the initiative, thoughtfulness and utility [of the booklet]. This could be used across all sections as a lot of patients are unsure and this is also a good ice breaker providing options." Another respondent said, "…It is a great idea to provide something like this to patients before they attend the clinic."

The majority of HCPs also rated the content of the booklet as appropriate, easy-to-read, appropriately demonstrative of good use of images and clearly presented, which reflect the readability score of the booklet as appropriate for individuals with mild ID (Webb, 2019).

One respondent wrote, "[The booklet is] clearly set out and ability to personalise for the

client which I think will contribute to engagement and understanding." The positive commentary was also seen in another response: Easy to read, inclusive of someone with ID to participate, encourage support person to be involved."

Adjustments to Booklet

In consideration of Rodgers and colleagues' (2004) and Owens' (2006) guidance for creating an effective resource, we reviewed and modified the booklet based on the improvements suggested from the survey, and the recommendations from the Easy to Read experts and PWID. The revised draft is included as a supplement (Supplement 2)

Content – Recommended Removal

Four respondents recommended removing the repetition of; 'you can say no to anything'. For example, one HCP suggested,"[This wording] might raise concerns that the proposed [health] checks can be harmful." As the use of repetition in patient guides has been suggested in the literature (Smith et al., 2012, Walker and Schuler, 2005) and by Easy to Read experts and PWID who participate in the NSW CID, we elected to keep the same frequency of the phrase's repetition.

Four respondents also raised concerns regarding the description of the role of a genetic counselor: "helps the doctor explain things to you." A respondent wrote, "Change this to … [a genetic counselor] knows a lot about genetics also and can help you and your family understand this information."

We amended the booklet's description of the role of a genetic counselor as suggested above.

Content – Recommended Additions

Thirty HCPs identified the need for additional information on "the what and the why" of a genetics appointment, including explanations of genetics and its relevance to health as well as why certain health checks, questioning and tests were being done. A description of this comment is explained by one respondent:"[The booklet doesn't address why we do things in genetics clinic, or that the underlying reason is to look for causes for ID and clarify offspring risk."

Based on the feedback provided by survey respondents, we further clarified what a visit to the genetics clinic would involve, while keeping the information brief and succinct as per the recommendations from the consultancy service from the CID.

Personalization

Thirteen HCPs were concerned that if the booklet was personalized to include photos and details of staff members, last minute staff changes might cause increased distress for clients, since they might have been expecting to see someone else. A respondent explained, "Team members…change on the day or over time[which] may cause confusion [for the booklet viewers]." This thought was echoed by another HCP: "Having a photo creates expectations, so if a different 'face' shows up, [this] could cause anxiety [for the patient]."

Ten HCPs felt that customization would not be possible due to limited resources and/or time, which was expressed by one HCP through their response: "Having it personalized would be ideal, however I am not sure our current admin staff resourcing would allow that." Another respondent said, "[I am] not sure [that] the extra work it would take to personalize the booklet to each visit would have enough added benefit."

With this feedback in mind, we created a general version of the

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booklet which could be used broadly and another version that could be personalized with pictures to fit the individual needs of a genetics service, thus keeping with the aims of the development of the booklet.

Discussion

This study aimed to develop a booklet intended to be read by people with mild ID and their carers prior to a genetics appointment and to do so with the involvement of PWID and an Easy to Read consultancy service. Such a project was initiated to address the lack of this type of resource and its need in the healthcare community and literature. was Approximately 70 individuals, the majority of whom were HCPs, evaluated the booklet and whether it

represented an appropriate information guide for this population. . Previous literature has identified that health services and patient experiences can be improved if they receive information in an accessible and easy-to-read format (Ali et al., 2013; Forshaw et al., 2017). Appropriate health information distribution enhances satisfaction of care, namely the concept of patient preparedness.

Evidence suggests that the root cause of inadequate preparation before an appointment is unlikely to be a patient's lack of motivation to learn more about the appointment, but rather the misunderstanding of often-complex concepts (Smith et al., 2012). Smith and colleagues (2012) suggest that using targeted language in educational interventions such as Easy to Read booklets for PWID can improve understanding and preparation for appointments.

Additionally, other studies demonstrate that uncertainty was a main inhibitor to patient preparedness, while conversely, informing patients of what to expect was identified as an enabler (Forshaw et al., 2017). The majority of HCPs who had experience with PWID as clients reported that the booklet reflected a typical genetics appointment and that they would provide it to PWID and/or their carers prior to their appointments. This feedback suggests that this resource can realistically inform patients about what to expect at a genetics clinic visit, thereby reducing patient uncertainty and improving preparedness (Forshaw et al, 2017).

However, we recognize that this pre-emptive strategy may have an effect opposite of that which is desired. For example, HCPs reported that PWID may become distressed at the prospect of having a blood test or seeing an image of it, which is a concern described by studies showing that blood tests are one aspect of the annual health check that can cause anxiety for people with learning disabilities (Perry et al., 2010; Goldsmith et al., 2013 and Edwards et al., 2011). Thus a challenge in generating Easy to Read booklets for PWID is to balance the importance of delivering information in line with patients' individual needs, without limiting the accuracy of the content to the point where it creates unrealistic expectations, which could negatively impact their sense of preparedness (Forshaw et al., 2017). With regard to the blood-drawing image, we decided that as most Australian laboratories are able to do the majority of diagnostic genetic tests on saliva samples, this image and the text could be omitted from the booklet without compromising its accuracy. However, we acknowledge that for services where blood sample collection is still an essential part of a clinic appointment, the booklet could either be adapted by reinserting the image and text, or providing a specific booklet aimed at preparing patients for blood-draw (for example the booklet from Me first: What will Happen at my Blood Test https://www.mefirst.org.uk/resource/childrens-easy-read-blood-test/). In addition, allowing patients the opportunity to discuss their concerns about blood-draw may be particularly useful in reducing any misperceptions or distress, further facilitating a sense of preparation (Forshaw et al., 2017).

Additionally, some patients may feel upset, confused or anxious if their expectations of the appointment are not met. This underlies a difficulty often faced when developing accessible information: the ideal resource is not too generic nor too specific. A designed resource, even when developed with the intention of balanced information, may not be appropriate for some members of the target population. For example, in this study, some HCPs suggested customization of the booklet would be beneficial (e.g., adding images of the hospital and staff), whereas others felt this might upset PWID if the imaged staff member was not present at the appointment. Genetic counselors were more inclined to support inclusion of pictures of staff that the patients would meet compared to clinical geneticists. One explanation for the significant association between genetic counselors and the idea of booklet personalization could be that one of the many roles of a genetic counselor is to be a patient advocate by providing information supporting individuals within the context of their personal and familial situations (Farwig et al. 2010). A personalized pre-clinic information booklet fits with this role of advocacy and the similar value of a patient-centred approach. However, around half of HCPs felt personalization was likely to be difficult and too onerous in terms of the time and resources it would require. Genetics workforce issues were reported, such as last-minute changes in available staff or clinic locations, which could cause some clients undue anxiety (Hoskovec et al., 2018; Horn and Parker, 2018; Finucane, 2010 and Scheepers et al., 2005).

To address these opposing views, two versions of the booklet were designed: one that could be customized and another that was more generic.

Previous studies have shown that tailored information resources can be used to supplement and enhance patient-targeted interventions. Walker and Schuler (2005) described a small pilot study testing the effectiveness of an orientation program among newly diagnosed cancer patients. The orientation consisted of a patient tour of the facilities, along with written information about the clinic, and a question and answer session with an oncology counselor. Patients who received the intervention were more knowledgeable about clinic procedures and more satisfied with their care compared with those who did receive the intervention The findings suggested that targeted patient programs utilizing multiple strategies may have better outcomes than using one format alone; There is potential for Easy to Read resources to add to other available patient-centred interventions geared toward genetics services and other healthcare services that frequently interact with PWID (e.g., occupational therapy, neurology or general surgery).

Study Limitations

One of the main limitations of this study was that the views of a large population of PWID and their carers have not yet been included. Inclusion of many PWID and their carers was outside the scope of this initial study to create and evaluate a booklet. Of note, the initial

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drafting of the booklet intentionally included PWID and an Easy to Read Consultant in accordance with Rodgers and colleagues' (2004, 2005) recommendation to include PWID at all stages of resource development. Moreover, the HCPs surveyed were limited to Australia and therefore the findings of this study are not necessarily generalizable to genetics services internationally.

Future Research

The updated version of booklet that addresses the pilot evaluation findings will be submitted to the NSW Council for Intellectual Disability for further feedback. Continued involvement of PWID and Easy to Read experts is of priority in all developmental stages of booklet. This version will then be evaluated by PWID (i.e., the intended end-users) and their carers in a planned future study. This will enable us to produce a fully evaluated and likely a customizable booklet, which will be transferrable across national genetics services. We intend for the final product to be downloadable from the Internet. This booklet may also be utilized as a guide for development of further resources to address topics, such as genetic testing, return of genetics results and the informed consent process.

Practice Implications

The use of Easy to Read resources (such as the one described in this study) is supported by experienced HCPs. Given an inclusive model of care has been demonstrated to improve outcomes for PWID (Iacono & Davis 2003; Ali 2013), providing an Easy to Read booklet describing a clinical genetics service prior to an appointment is likely to benefit patients by providing the opportunity for prior-appointment preparation.

Conclusion

An Easy to Read booklet intended for people with mild intellectual disability, including a version that can be customized, has been developed. This resource has been designed to prepare PWID prior to a genetics appointment and to encourage their participation during the visit. The booklet has been evaluated by clinical geneticists and genetic counselors who reflected that they would support its use in their practice. As such, our hope is that the booklet will better support PWID, reduce healthcare inequities, and empower PWID in their own healthcare decisions that influence their well-being and healthcare outcomes.

Author Contributions

Ms. Huafrin Kotwal was involved in the design and development of the project undertaken as a component of the Master of Genetic Counseling program throughThe University of Sydney and was involved in all elements, including evaluation and dissemination of results and writing of the manuscript.

Dr. Jane Fleming was involved in development and design of the research project, evaluation and dissemination of results and writing of the manuscript.

Professor Kristine Barlow Stewart wasinvolved in development and design of the research project, evaluation and dissemination of results and editing of the manuscript.

Ms. Jackie Boyle assisted recruitment and was involved in development and design of the research project elements, including evaluation and dissemination of results and writing of the manuscript.

Dr. Letitia Silberbauerassisted recruitment and was involved in development and design of the research project, including evaluation and dissemination of results and writing of the manuscript.

Dr. Melanie Leffler assisted recruitment and was involved in development and design of the research project, including evaluation and dissemination of results and writing of the manuscript.

Ms. Lucinda Murray assisted recruitment and was involved in development and design, evaluation and dissemination of results and writing of the manuscript.

Dr. Elizabeth E. Palmerwasresponsible for oversight of the research project and recruitment and overall planning and completion of the project. She also assisted recruitment and was involved in development and design, evaluation and dissemination of results and writing of the manuscript.

All authors reviewed the publication draft and approved the submitted version.

Acknowledgements

Special thanks to the NSW CID for their previous and continuing expertise and advice in the development of the booklet and to the HCPs who gave their time to provide valuable evaluation of the booklet.

Conflicts of Interest

Author Dr. Elizabeth Palmer, Author Huafrin Kotwal, Author Dr. Melanie Leffler, Author Lucinda Murray, Author Associate Professor Kristine Barlow-Stewart, Author Dr. Letitia Silberbauer, Author Dr. Jane Fleming declare they have no conflict of interest.

Human Studies and Informed Consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975 as revised in 2000. Consent was implied by completion and submission of an online survey as outlined in the survey participant information statement and invitation to participate, defined before clicking the button to start the survey.

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