'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA)

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Abstract

Background: Recent investigations provide evidence of stigma against people with a diagnosis of mental illness.

Aims: The purpose of this study was to provide an account of the life experiences of persons with schizophrenia. Focusing on the individuals' personal reports of events and situations, the issues of stigmatisation and discrimination were explored.

Method: Six participants were interviewed using a semi-structured schedule focusing on the areas of personal history, understanding of schizophrenia, social and medical contextualisation, and reflection on impact. The research was conducted using Interpretative Phenomenological Analysis (IPA) (Smith, 1996, 1999).

Results: Super-ordinate themes of judgement, comparison, and personal understanding of the (mental health) issue emerged. Stigma was evident both as public-stigma and as self-stigma. Conclusions: The ramifications of stigma and discrimination are enduring and potentially disabling. IPA is a constructive tool in exploring these issues.

Declaration of Interest: None

Keywords: IPA, schizophrenia, stigma.

Introduction

Recent investigations have reported that individuals with schizophrenia and other mental illnesses endure stigmatisation (see Farina, 1998; Hayward & Bright, 1997, for reviews). Empirical investigations (Wahl, 1999) and first-person accounts (Gallo, 1994) report that for certain individuals, stigma can prove

persistent and disabling. Sartorius (2001) proposes, 'There is no greater issue than stigma. It is the most important barrier facing mental illness today'.

To provide a clearer understanding of stigma, recent research has distinguished public-stigma from self-stigma (Corrigan, 2000; Corrigan & Penn, 1999). Public stigma is the reaction to mental health consumers by the community; self-

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stigma is the reaction by the consumers to themselves in light of their experience of mental illness and/or public-stigma. Investigating self-stigma, Link (2001) proposes that from early life, an individual develops expectations and beliefs that may have serious implications for individuals with mental illness, as developed attitudes, stereotypes, and potential prejudices become personally relevant (see also Corrigan & Lundin, 2001). The consequence of this is that an individual may consider whether other persons will discriminate against them. Thus, being linked to stereotypes, and 'labelled' (Link et al., 1987, 1989) may affect an individual's self-esteem. Furthermore, the diminished self-efficacy that results from self-stigma may interfere with aspects of rehabilitation including independent living opportunities and motivation to obtain competitive work (Link, 1982; Wahl, 1999).

Research into mental health consumer opinions of stigma has commonly utilised survey design methodology (Dickerson et al., 2002; Wahl, 1999). The benefits of this approach include greater sample size, representativeness, and insight into demographic and clinical co-variables. The limitation is that the survey focus is researcher driven, with little participant autonomy. To draw on individual consumer responses, a new and more flexible approach must be undertaken. Qualitative research provides a forum for the perspectives of those who are traditionally excluded from academic discourse (Farber & Sherry, 1993). Strauss & Corbin (1990) outline its focus as on people's lives, stories, behaviour, organisational skills, social movements or interactional relationships. An emphasis is placed on the suitability of this approach to uncover the personal nature

of an individual's experience within illness.

Oualitative research through first person narratives provides valuable information on the deleterious effects of stigma that is particularly salient in the domain of recovery (Kotake Smith, 2000; Young & Ensing, 1999). Autobiographical accounts 'help us refocus our thinking beyond the myopic and outdated deficit perspective' (Ridgway, 2001, p. 336), with public and self stigma seen as key barriers to this recovery process. Prior to recovery, the individual may lose their sense of self as a whole person, and view themselves as defined only by their diagnosis (Ridgway, 2001). 'Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed' (Leete, 1989, p. 199).

Through in-depth analysis, further understanding of the wider ramifications of stigma may be learnt. The internalisation of stigma prevents the individual from coming to terms with the psychiatric disability. Reflecting on the negative public image of mental illness, Kotake Smith (2000) states, 'It is so hard to accept yourself as being mentally ill when that's the kind of picture that the society draws of you' (Kotake Smith, 2000, p. 154). Recovery commences only when that acceptance is arrived at, and the need for help from others is acknowledged (Kotake Smith, 2000). However, the inability to connect with others and form meaningful and trusting relationships to aid that recovery is compounded by the sense of exclusion. 'I needed to be able to relate to other people what I felt – why I felt so stigmatised by my illness that I couldn't relate to anybody. I felt very alone and very lonely' (Young & Ensing, 1999, p. 227). It is through these in-depth personal accounts of life experiences that the varied and multiple ramifications of mental illness are uncovered. The aim of the present investigation is to maintain this quality of information, and further knowledge of how these factors interact.

The qualitative method – Interpretative Phenomenological Analysis (IPA)

Qualitative-based studies have commonly utilised social cognition or discursive theoretical analytic approaches. Social cognition aims to focus on the inner mental state of the individual, and assumes a link between verbal data and underlying cognitive activity. Discourse analysis (e.g. Potter & Weatherell, 1987) regards verbal data as behaviour in itself, and directs attention to the context in which the discourse takes place. Where discourse analysis utilises qualitative reading of specific text, social cognition adopts a standardised quantitative approach to data interpretation. However, these approaches contain inherent difficulties for the present investigation, which aims to examine the association of verbal report, behaviour and cognition, without discounting potentially key themes due to their frequency within the

Interpretative Phenomenological Analysis (IPA) (e.g., Smith 1996, 1999; Smith *et al.*, 1997) presents an alternative perspective to this situation (see Crossley, 2000; Giles, 2002, for further methodological comparisons). IPA focuses on cognitions and experiences (as in social cognition), using qualitative examination of the text outcome (as in discourse analysis). It has its theoretical foundations in phenomenology and symbolic interactionism, which emphasise

subjective perception and the importance of individual interpretation respectively. IPA states, 'Access is both dependent on, and complicated by, the researcher's own conceptions which are required in order to make sense of that other personal world through a process of interpretative activity' (Smith, 1996, p. 264).

Research utilising IPA has primarily been in the field of health psychology. Recent investigations have focused on chronic pain and chronic illness (Osborn, 2002; Reynolds, 2002); reproductive health (Chadwick & Liao, 2002; Todorova, 2002); and psychological distress including self-harm and attempted suicide (Alexander, 2002; Crocker, 2002). IPA has rarely been used to study people with psychosis. The focus has been the evaluation of delusions (Rhodes & Jakes, 2000), recovery (Thornhill & Clare, 2002), and treatment strategies for hallucinations (Coupland, 2002; Newton, 2002). These studies have provided insight into the experience of psychosis, informed clinical intervention (Newton, 2002), and highlight the potential of IPA in exploring life experiences and social exclusion.

The rationale for this investigation is to provide an in-depth consumer perspective of particular issues inherent in living with a diagnosis of schizophrenia. The aim is not to create a representative study, but to understand the manner in which stigmatisation impacts on the lives of certain individuals.

Methodology

Participants

The data were derived from interviews with six participants. The sample size was guided by Smith *et al.* (1999), and is

commensurate with recent IPA-based investigations (Adolphus, 2002; Lea, 2002; Newton, 2002; Robb, 2002; Robson, 2002). The sample was drawn from previous quantitative-based stigma studies (Knight *et al.*, 2001, 2002) of those outpatients who had indicated perceptions of stigma on the Devaluation-Discrimination scale (Link, 1985, 1987), were not currently experiencing acute psychosis, and who had agreed to undertake further research involvement. The first six consumers approached consented to take part in the study.

Participant information is provided in Table 1. All individuals reside in central urban districts of the UK. In the following accounts, names of people and places have been changed to preserve anonymity.

Procedure

Qualitative data were obtained through interviews with participants that lasted between 30 and 100 min, which were tape-recorded for later transcription. Written informed consent for the study and the recording was given by participants prior to the interview. Participants were reimbursed for their time.

The interviews were conducted with discussion focussing on four principal areas:

- The individual's life history.
- Personal experience and understanding of their mental health issue (henceforth referred to as 'the issue'). This included questions as to why the interviewee had visited mental health services, the quality of treatment received, and preferred ways of daily coping.
- Social understanding of the issue, and how it is contextualised within their life. Questions were presented with a dual focus. First, how people with this 'issue' are viewed by society, and second, how the interviewee personally feels he/she is viewed both by society and by close personal contacts. Issues of selective disclosure and underlying rationales were raised.
- Reflection on the impact the issue has had on their life. Questions were focused on self-perception, identification or rejection of 'ill' status, and putative ramifications for the future. The final

Gender	Male Female	4 2
Age in Years	Range Mean	31 – 50 43
Clinical Diagnosis	Schizophrenia Paranoid Schizophrenia	3 3
Contact with Mental Health Services in Years	Range Mean	3-35 16
Number of Hospitalisations (participant $n = 5$)	Range Mean	1-9 3.6
Current Status	Outpatient	6

question asked specifically whether the term 'stigma' held any personal relevance for the interviewee.

The semi-structured approach enabled the interviewee to discuss issues of prime concern or interest to themselves, and as such, the interview is neither rigid in sequence nor in usage of all questions stated. Questions were kept deliberately open, providing cues for participants to talk with a minimum amount of interruption or constraint by the interviewer. A greater number of questions than commonly used in IPA investigation were prepared in light of research demonstrating potential difficulties in interviews with participants with psychoses (Newton, 2002; see also Booth & Booth, 1996). The terms 'schizophrenia', and 'psychosis' were not used in the interviews unless mentioned by the participant. Kev terms to describe participants' situations (e.g. 'issue', 'illness', 'problem') were adopted by the interviewer (see Penn & Nowlin-Drummond, 2001, for discussion).

Analysis

The data were analysed using IPA, using the procedures outlined by Smith *et al.* (1999). The aim was to create a comprehensive account of themes which have significance within the original texts. Thus, connections were made from the dialogue, rather than from a pre-existing theoretical position.

Initially interviews were transcribed twice, independently by the principal researcher and by a mental health consumer in order to verify dialogue. Transcripts were analysed individually in sequence, by marking relevant items, identifying emerging themes, noting connections and ordering these into preliminary lists. These themes were then

grouped into associated clusters. Master lists of themes were then compiled for each interview, which incorporated these clusters. On completion of individual analysis, master lists of themes were compared from all interviews, and assembled together as sub-themes within higher order categories, entitled superordinate themes.

At all stages of the analytic process, constant reflection and re-examination of the verbatim transcripts was utilised to ensure that themes and connections related to the primary source material. with certain themes being dropped and others expanded. All themes were represented by extracts from the original text, but were not chosen purely for their prevalence. 'Other factors, including the richness of the particular passages which highlight the themes, and how the theme helps illuminate other aspects of the account, are also taken into account' (Smith et al., 1999, p. 226). The primary analysis was contingent upon the interpretation of the principal researcher, and an independent researcher experienced in IPA methodology conducted external reliability of analysis. This confirmed the appropriateness of connections made between text and themes, appropriate clustering, and representation of the original content within final categories.

Results and Discussion

Three super-ordinate themes that were primarily phenomenological in composition were drawn from the analysis, (i) Judgement, (ii) Comparison, and (iii) Personal Understanding of the Issue. The underlying thematic structure of the results is displayed in Table 2. Endorsement of all super-ordinate

themes was demonstrated within each participant text.

Judgement (Table 2: Code 1.)

The super-ordinate theme of Judgement emerged from the anticipated and actualised reactions that participants encountered from friends and family. authority figures representing medicine and the police, and society in general (Code 1.1.). Responses were congruent with a social cognitive perspective of public stigma in that they were comprised of stereotypical attitudes, prejudice and discrimination. Attitudes (Code 1.1.1.) mentioned were predominantly negative, and illustrated a general paucity of knowledge, 'They don't understand, people don't understand things that happen to people' (Poppy, text line 112), 'People don't understand. I mean, they'll say, is it split personality or something basic like that' (Joan, 233).

Prejudice (Table 2, Code 1.1.2.), concurrence with negative stereotypes, was widely evident. Paradoxically, the source of this prejudice was often from where the individual was seeking help. 'Part of society sees schizophrenics as dangerous and unacceptable. I have had it from my parents, my family and my friends, my close encounters' (Paul, 483). Sartorius (2002) states that iatrogenic stigma is evident through labelling, legislation and symptom treatment. For the participants, it was manifest during their frequent interactions, 'Even by doctors. They don't see you as a person that's O[K], not OK, but acceptable' (Gary, 51), 'Mainly like it was the psychiatrist versus us lot' (David, 329). Drawing a parallel between the social exclusion experienced by other minority groups, David acknowledges, 'There's a very prejudiced [break] racist view against

mental illness. [break] Especially from the police' (156).

The behavioural reaction to the cognitive and affective response of prejudice is discrimination. Discrimination (Code 1.1.3.) had been experienced from both familial and societal interactions with ramifications on both the living and work environments. "You're schizophrenic..., you cannot move in" (Paul, 394). 'We're not accepted when we go back to work, no matter that you do the job. They don't treat you as an equal, they're always a bit wary of you, [break] from my experience' (Gary, 127).

For the participants, the ramifications of the diagnosis and the judgements were extensive in terms of their self-concept, and daily experience (Code 1.1.1.1.). Individuals felt labelled as 'extremely different [break] unacceptable' (David, 534), 'dirty, unacceptable' (Ken, 559), with 'such a bad, bad image' (Joan, 498). Acknowledging personally held prejudicial attitudes brought a further sense of responsibility for the impact of the illness. 'I didn't know too much about mental illness. [break] And I think that my attitude before OK, has, is perhaps caused some sort of friction on myself, in terms of healing myself' (Ken, 453). Thus the individual has experience as perpetrator and victim of stigmatising attitudes, accentuating the current selfstigma. Investigating lay theories of schizophrenia. Furnham & Bower (1992) found that most respondents rejected a moral-behavioural model for the aetiology and behaviour of persons with schizophrenia. However, the notion that persons with mental illness are culpable for its onset, and therefore to blame for their symptoms, has found support. Dain (1992) states that blaming attributions towards persons with mental

Table 2: Compositional structure of IPA themes

Thematic level	Code	Theme One	Code	Theme Two	Code	Theme Three
Super-ordinate theme	I.	Judgement	2.	Comparison	3.	Personal understanding of issue
Master themes	I.I.	Source of Judgement	2.1. 2.2.	Self – Self Self – Others	3.1. 3.2.	Health Coping
Sub categories	I.I.I. I.I.2. I.I.3.	Attitudes Prejudice Discrimination	2.1.1.	Past, Present, Future Self 3.1.1.	3.1.1.	Illness – Recovery
Sub Categories	1.1.1.1.	Effect on Life	2.2.1.	Inclusion – Distinction	3.2.1. 3.2.2. 3.2.3.	Avoidance – Withdrawal Education Secrecy

Key: Code indicates thematic hierarchy

illness are congruent with the notion of sin widespread in American Christianity, and continue to find endorsement. Many people do not adhere to a medical model of illness (Corrigan & Penn, 1997), and the current texts demonstrate that consumers may remain adherent to aspects of a moral rationale.

Comparison (Table 2, Code 2.)

The second super-ordinate theme. Comparison, is representative of the intra and inter-personal dilemmas evident in the text. First, participants discussed how their lives were, are, and will be affected as a direct cause of their illness (Code 2.1.1.). Reflecting on their earlier life as a person unaffected by mental illness, issues of normality, ability, and happiness were contrasted with current life situations. 'Before, I was normal I could go to work, and I could live my life' (Poppy, 54), 'If I could just get back to who I was before this illness started I'd be very happy but I can't' (Joan, 87). Participants viewed their lives as having undergone a qualitative shift, which for many appeared irreversible. 'I worry that, that I'll never be normal again' (Poppy, 286). Levey & Howells (1995) propose that individuals with mental illnesses are commonly viewed as 'different', and that this perceived differentness may lead to fear, which is at the root of stigma. That this distinction is apparent when viewed from the consumer perspective is reinforcement that predominantly, consumers are lay persons, in whom developed stereotypes and prejudices have attained personal relevance (Link, 2001). Paradoxically however, it is also through this distinction that the most positive descriptions of life with mental illness are discussed. 'There's a good and bad side to everything. [break] OK and I feel that what I've gone through. I've discovered some things that I don't think I would have known about had I not gone through this' (Ken, 291). 'If I was just a normal person [break] lead life like [break] a robot or a number [break] just a number in a factory, just being of the rat race' (David, 341). For several participants, they believed their experience had afforded them the opportunity for intellectual and personal development, and from that, a sense of liberation.

Nevertheless, discussing the abstract concept of how life would be different without mental illness proved a difficult task. 'I don't know how to put this but, I've never thought like that. [break] It's just, I can't. I'm sorry, I just can't' (Gary, 276). Perceptions of future life were similarly grounded with the expectation of continuing mental illness, 'I don't know that you have much of a future with this illness because the future is, they say it gets better as you get older but I'm not finding that' (Joan, 469), 'I don't have a future' (Poppy, 272).

The second component of Comparison is the sense of inclusion within, and the distinction from social cliques (Code 2.2.1). There appears an evident struggle between belonging, and keeping oneself separated from a group that does not have a positive social identity. 'Places like [day-centre] rather downhill and depressing, because of the type of people that go in there' (David, 28), 'My friends that I meet at the voices group, it's weird that voices group because they are all about as mental as each other but there's a solidarity in people' (Joan, 505). It is through these common experiences that a sense of understanding and tolerance is gained, 'Some people have mental illnesses, sometimes they're more compassionate than others, OK. They are more friendly, more compassionate' (Ken, 917).

There is also a desire to belong to the mainstream society, 'I'm putting myself on that, on that spectrum to make myself feel comparable and acceptable to society, and that really I'm part of the same rail but on a different part of it' (Ken, 1029). Yet, the distinction of normality and abnormality remains evident, 'I'm not like everybody else am I? [break] I have problems. [break] Other people suffer them, but you know, ordinary people don't.' (Poppy, 140), 'Normal people don't have these experiences' (David, 203).

Personal understanding of issue (*Table 2*, *Code 3*.)

Focusing on health (Code 3.1.), and mechanisms of coping (Code 3.2.), this final theme provides insight into the participants' conceptualisations of their life situation. Reflecting on whether they view their situation as being 'ill' (Code 3.1.1.), participants demonstrated that it was a decision in which they played a passive role, 'I don't..., I, I do because people tell me that I'm ill' (Poppy, 243), 'I've been told I'm ill, so I believe it' (Joan, 427). The term 'ill' appears unable to capture the breadth of experiences encountered. For many, this is a battle, 'The nature of this illness is that it takes over if you let it' (Joan, 26) 'Because I'm so desperate to get myself better, I would say anything and everything to get myself better' (Ken, 792). In essence, 'life is a sort of struggle for survival' (Joan, 381).

The second sub-theme identified was coping. Link *et al.* (1991; see also Goffman, 1963) identified three primary methods of stigma coping; avoidance-withdrawal, education, and secrecy, that may incorporate shifts in mental state or in behaviours. However, the application

of these coping orientations has been demonstrated as having 'consistent effects in the direction of producing more harm than good' (Link et al., 1991, p. 302). Analysis of the texts showed that participants frequently used these coping methods. with avoidance-withdrawal (Code 3.2.1.) widespread, 'I don't go out my house. [break] I stay in my house' (Poppy, 255), 'Sometimes I break off [break] don't bother to contact them' (David, 244). Gallo (1994) states that although avoidance may be viewed as a protective strategy, the consumer reinforces the sense of societal exclusion by 'exhibiting the proper deference to those above me ... all other human beings' (Gallo, 1994, p. 408). In believing these thoughts, self-stigmatisation may prove self-consuming, and potentially threatening (Gallo, 1994).

Education (Code 3.2.2.), which refers to informing people about one's individual life situation, was advocated to preempt potentially negative situations that may arise later. 'I've always adopted a policy of telling people, you know, they'll find out. 'Cos we are different' (Gary, 107). Having encountered hostility following disclosure however, his views have modified. 'I don't tell members of the public. I mean people I don't know, not any more. [break] They think you're a f**king [break] nutter'. For others, the wish to disclose information was similarly overridden by concerns about the effects of doing so. 'It's not so easy to, to explain to people' (Joan, 168), 'I'm at a stage where I would like to tell anybody OK, but [break] it's not understood by people' (David, 515). Farina et al. (1971) demonstrated that consumers who believed others knew about their psychiaperformed tric history tasks adequately, and felt less appreciated in

their efforts. A negative cycle was perpetuated as neutral observers then viewed the individual as more tense and poorly adjusted.

Participants adopted a policy of secrecy (Code 3.2.3.), 'I wouldn't tell, I wouldn't tell other, other friends. [break] Because they would judge me' (Poppy, 161), 'I especially, try to keep it a secret about my mental illness when I'm in the normal outside world' (David, 589). Specific concern was demonstrated with regard to disclosure to the police, following previous incidences experienced personally or by friends. 'I wouldn't tell the bl**dy police' (Joan, 329), 'I wouldn't tell the police [break] if I ever got into trouble' (David, 254). Utilising workshop scenarios with consumers and police officers, Pinfold (2001) found that for certain individuals the experience of education and interaction had personal benefit, while others found it perpetuated the sense of social division. This highlights the individual and variable success of the stigma coping orientations, and demonstrates the great need for change on a social scale, to assist the recovery of people with a diagnosis of mental illness.

Conclusion

The findings demonstrate certain intra and inter-personal ramifications of having a mental illness, as perceived by a small group of individuals with a diagnosis of schizophrenia. For these consumers, public stigma is evident through prejudice and discrimination, from a plethora of sources including family, friends, society, police, and mental health professionals. Self-stigma reveals similar prejudice, lowered self-esteem, and an ongoing struggle for acceptance within social cliques. In addition to the social

withdrawal experienced as a negative symptom of schizophrenia, the participants expressed how they believed stigma had led to behavioural changes (see Link et al., 1989, 1991). Individuals were leading isolated lives, and felt their own identity subsumed within a 'diagnosis' identity. The struggle to retain a positive sense of self, and aim for recovery, thus requires concerted effort from the consumer, with support, understanding and acceptance from the macro and microsociety that surrounds him or her.

The current study reaffirms many themes prevalent within stigma literature, such as loss of identity, sense of exclusion, and various methods of coping. This is beneficial in increasing the salience of stigma as a threat to consumer quality of life, and in validating the utility of IPA. Crossley (2000) highlights the potential difficulty that phenomenological approaches present a romanticised 'insider' view of illness, that 'tends to celebrate the authority of the individual' (Crossley, 2000, p. 34), and challenges authority the of professionals. This paper asserts that the current findings are congruent with previous empirical investigations into stigma (Knight et al., 2001; Wahl, 1999), and that furthermore, in order to provide a holistic investigation into the experience of mental illness, the 'expertise' of the mental health consumer must be recognised as both valid and integral to increasing knowledge and understanding (see Corrigan & Penn, 1997, for discussion). Davidson et al. (2000) state that this approach 'will prevent us from simply rehashing our own preconceived, largely medical, notions of disorder, and will assure the relevance of our interventions to our patients' day-to-day lives' (Davidson et al., 2000, p. 154).

In addition to increasing our depth of knowledge on existing issues, two further points are raised. Do the results tell us anything new about stigma, and if so, how can that benefit clinical practice? The texts illustrate the intensity of the stigma experience. For certain individuals, positive symptomatology alleviated many years previously, yet the label and shame of schizophrenia remains a personal and social burden. That participants maintain a qualitative distinction between consumer and nonconsumer emphasises the perceived intra-personal shift that occurs following illness onset. Together, these factors contribute to what can appear an almost insurmountable barrier to recovery. Conversely, certain participants felt the experience afforded a sense of personal and intellectual liberty from the constraints of normal society. There is thus a dichotomy of freedom and restriction, albeit negatively weighted to the latter. Finally, although clients relayed being formally diagnosed as 'schizophrenic', it was apparent that they had either not been given in-depth explanations of schizophrenia, or had been given information that was difficult to fully comprehend. Subsequently, certain participants attempted to assimilate their personality, moods, and life status into a model of dissociative identity disorder (DID), believing they had a 'split-personality'. Critically, the consumer should be informed about the issue to the best of the clinician's ability to counter stereotypes and myths which compound the difficulties faced.

Within this study, the themes of judgement, comparison and personal understanding of the issue elucidate the pertinent concerns of six individuals. Examination of such themes may form

a productive foundation from which to conduct new empirical research and inform therapeutic intervention (see Davidson et al., 2000; Newton, 2002). Clinical practice could benefit greatly from further exploration of the issues raised, and providing clear explanations of the multifaceted nature of schizophrenia. It should further highlight potential positive aspects of experiencing the 'issue', and ultimately attempt to develop informed coping orientations to assist the consumer through this traumatic event. IPA should be viewed as a constructive tool in this process, whose emergence will benefit researchers, clinicians, and vitally, the consumer

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