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Matching researchers' needs and patients' contributions: practical tips for meaningful patient engagement from the field of rheumatology

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ABSTRACT

There is an increasing recognition of the importance of patient engagement and involvement in health research, specifically within the field of rheumatology. In general, researchers in this specialty appreciate the value of patients as partners in research. In practice, however, the majority of researchers does not involve patients on their research teams. Many researchers find it difficult to match their needs for patient engagement and the potential contributions from individuals living with rheumatic disease. In this Viewpoint, we provide researchers and patients practical tips for matching 'supply and demand,' based on our own experiences as patient engagement consultants and trainers in rheumatology research. All authors started as a 'naïve' patient or caregiver, an identity that evolved through a process of 'adversarial growth': positive changes that are experienced as a result of the struggle with highly challenging life circumstances. Here, we introduce four stages of adversarial growth in the context of research. We submit that all types of patients have their own experiences, qualities and skills, and can add specific input to research. The recommendations for engagement are not strict directives. They are meant as starting points for discussion or interview. Regardless of individual qualities and knowledge, we believe that all patients engaged in research have a single goal in common: to contribute to research that ultimately will change the lives of many other patients.

INTRODUCTION

There is an increasing recognition of the importance of patient engagement and involvement in health research, specifically within the field of rheumatology.¹ In general, researchers in this field appreciate the value of involving patients as partners. In practice, however, the majority does not involve patients on their research teams.

Many researchers find it difficult to match their needs for patient engagement and the potential contributions from individuals living with a rheumatic disease.²⁻³ Researchers may have different questions to ask these patients, such as: What is it like to live with this disease? Is my research question relevant to patients? Is my patient information folder readable? Could you comment on my research proposal? On the other side, there are different types of patients willing to be engaged in research teams or projects, varying from people who have just been diagnosed, to members of patient associations and trained patient research partners (PRP).⁴⁻⁵ What is the best way to match researchers' needs and patients' contributions, to

make engagement meaningful and sustainable, help patients avoid tokenistic situations and to avoid misunderstandings and disappointments for everyone?²⁻⁶⁻⁸

In this Viewpoint, we provide researchers and patients practical tips for matching 'supply and demand'. We use patient engagement as an overall term, covering a range of roles. Some patients are PRPs: equal partners in research teams. We refer to that as patient involvement. For the purposes of this paper, we are not addressing individuals who are study participants.

Almost all PRPs—including the authors—started as a 'naïve' patient or caregiver, an identity that evolved through a process of 'adversarial growth': positive changes that are experienced as a result of the struggle with highly challenging life circumstances.⁹⁻¹¹ Here, we introduce four stages of adversarial growth in the context of research. These stages are based on the literature about adversarial growth: with an 'earthquake' as starting point, via personal strength to helping others.⁹⁻¹¹ We combined this with the description of growth in the literature on patient involvement in research: from 'experience', via 'experiential knowledge' to PRP.¹²

For each stage, we added a vignette: a fictitious description of a person in this stage (see table 1). In table 2, we make recommendations for engaging patients in the four stages for specific researcher's questions, based on our own experiences as patient engagement consultants and trainers in rheumatology research. These recommendations are not strict directives; they could serve as a starting point for matching researchers' needs and individual patients' strengths. We submit that all types of patients have their own experiences, qualities and skills and can add their input to research in specific roles and activities. No type of patient is more important than others. We advise research teams to engage several types of patients in a research project, and in different roles.¹²⁻¹⁵

Stage 1: individual lived experience

In hindsight, many patients who live with chronic diseases describe their lives as a play in two acts. In the first act, they live as 'normal' healthy people. In the second act they live as people with a long-term condition, and they often grieve the first act. For most the transition between these two acts may take several years, from first signs to diagnosis and start of treatment.

This transition is often described as an 'earthquake': a disruption of core belief systems where



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Table 1 Four stages of adversarial growth in the context of research for people living with a chronic condition

	Stage 1 Lived experience	Stage 2 Personal story	Stage 3 Collective perspective	Stage 4 Patient research partner
Vignette	Christine (62 years old) has just learnt that she has a chronic illness. She doesn't know yet what that means for her daily life. She doesn't know anyone else with her illness and is anxious for the future.	William (68) was diagnosed with a chronic illness a few years ago. He can articulate his own illness story well. He hardly knows anyone else with his condition but has obtained information about his disease and treatment options.	Anouk (43) has lived with her chronic condition for some years. She has adjusted her life to it. Anouk meets many other patients in her own Facebook group. She has become aware of the heterogeneity of the patients' perspective and can share her own insights, opinions and experiences. She can also articulate what she has heard from fellow patients.	Samira (32) has been living with a chronic illness almost all her life. She is a board member of a patient association and speaks with many other patients as well as health professionals. She can share her own experiences, and the collective experiences of other patients. She has taken a basic research course for patient representatives.
Contributions to research	Recent authentic naïve personal lived experience	Articulated recent personal experience (experiential knowledge), willingness to share these experiences with others	Collective articulated experience (experiential expertise), awareness of the heterogeneity of the patients' perspective, insights in to patients' needs and preferences.	Collective articulated experience and research readiness: willingness to bring others' perspectives and to contribute actively the patients' perspective to research projects; awareness of research priorities.
Accessible for research through	Interview, focus group, survey	Patient story at conference or in education	Representing a group; providing advice	Patient partner, bridge between researchers and patients; open to collaboration as equal partner

Table 2 Matching researchers questions and needs, and patients strengths and limitations: recommendations* and arguments

Researcher's question	Lived experience Christine (see table 1)	Personal story William (see table 1)	Collective perspective Anouk (see table 1)	Patient research Partner Samira (see table 1)
What is your personal experience of living with this disease?	+ May be too early	++ Perfect match	+ Good match	- May know others who are better suited
What is your personal experience with the diagnosis?	++ Recent unarticulated experience	++ Recent, more articulated experience	- Personal experience with diagnosis may be outdated.	-- Personal experience with diagnosis will likely be outdated.
Can you read and understand the Patient Information Folder?	++ Perfect match	+ Good match	- May be too knowledgeable, loss of the naïve patient experience. Could ask other patients.	-- Too knowledgeable, has learnt research language. Could ask other patients
Do you think other patients are willing to be included in my study (as participants)?	- Doesn't know other patients	- Doesn't know other patients	++ Collective perspective: may not fully understand the study	++ Collective perspective: may understand the study
Is my research question relevant for this patient group?	-- Doesn't know other patients (speaks to personal opinion only)	-- Doesn't know other patients (speaks to personal opinion only)	++ Collective perspective	++ Collective perspective May be aware of patients' research priorities
What are important outcomes that I should include in my study?	-- Doesn't know other patients	-- Doesn't know other patients	++ Collective perspective	++ Collective perspective May be aware of patient relevant outcomes
Can you comment on my research proposal?	-- Doesn't know other patients; not research ready.	-- Doesn't know other patients; not research ready.	+ Collective perspective, may not understand the proposal.	++ Collective perspective, may understand the proposal.
Are you willing to be an equal member of the research team?	-- Doesn't know other patients; not research ready.	-- Doesn't know other patients; not research ready.	+ Collective perspective, not research ready; could join together with a more experienced patient.	++ Collective perspective; research ready.
Could you act as a 'critical friend' and push back on the research team if necessary?	-- Grateful to be included; not sure of good/bad partnership yet; not research ready.	-- Grateful to be included; not sure of good/bad partnership yet; not research ready.	- Grateful to be included; not sure of good/bad partnership yet; not research ready.	++ Understands more about being on a research team. Able to review critically and give constructive feedback. Ok to push back on research team
-- Strong recommendation not to engage. - Weak recommendation not to engage. + Weak recommendation to engage. ++ Strong recommendation to engage. *Recommendations (starting points for discussion or interview, no strict directives).				

basic assumptions about oneself are challenged.^{9–11} This may be confusing and frightening. They may lose control of many aspects of their life, and ask for example: Why did this happen? What is going on in my body? What does it mean for my work, friends and relatives? What are the consequences for my future? How do I regain control?

This confusing and painful period fundamentally changes their perspective on themselves and on health and illness in general. Everyone who has been there knows that the answer to the rhetorical question ‘Aren’t we all patients?’ is simply ‘No’.¹⁶

People in this stage—like Christine (see [table 1](#))—can contribute to research with their individual unarticulated naïve and authentic experiences. They have many questions, and few answers.

Stage 2: personal story—experiential knowledge

For many patients, it can take years to adjust their everyday life to their reality of living with chronic disease. This may involve painful choices that have a ripple effect on other parts of their life. They may need to lessen their workload or even leave employment. These choices often have consequences for the life of their partner and their family. The most challenging is acceptance.¹⁷ Regaining complete control of this situation, given the unpredictability of chronic disease, may prove to be impossible.¹⁸

Once they are able to make sense of the new situation, they are ready to formulate a new story of themselves (also called ‘a narrative’), including an adjusted perspective on the future.^{9–12} People in this second stage—like William—can contribute to research with their more articulated personal story that we refer to as ‘experiential knowledge’.¹² They are not able to provide insights for patients as a group, as they often do not know that many other patients (see [table 2](#)).

Stage 3: collective patient perspective—experiential expertise

As people living with chronic disease settle in to this day to day reality, they often seek answers from the medical community and seek practical, experiential answers from their peers in the disease community. One can find solace in knowing you are not the only one going through such a journey, and can learn ‘hacks’ or ‘tips’ from others living with their condition who have gone through similar experiences or are at the same place in life. Patients here learn from each other—they learn each other’s stories and experiences, and they see their similarities to and differences with others. They may also belong to specific patient organisations or communities.

People in this stage—like Anouk—may develop a desire to help others avoid having to face the same negative and alienating experiences they did.^{10–12} Based on their ‘experiential expertise’, they can contribute to research with a more collective and profound perspective. They can provide their own insights plus insights they have learnt from others in their patient community. They do not necessarily represent others’ opinions and experiences, but they can convey what they have heard and seen from their peers, and they are aware of the differences between patients. They may not be familiar with the research context and processes.^{8–19}

Stage 4: PRP—equal partner involved in research

Patients with a collective perspective may be invited by researchers to get involved in different types of research teams or projects. They may have international experience working with groups outside of their own country or have had the privilege to attend

and learn from other patients at international conferences. Over the years, they learn to understand the research context and processes.¹² They may need to learn skills (eg, communication) that help them better engage on a research team, or for example, on a guideline committee. They may receive some form of training in patient-oriented research,^{8–12} to become ‘ready to research’.¹⁹

In the field of rheumatology, this fourth stage is formalised as ‘PRP’.^{4–5} People in this stage—like Samira—can contribute to research with a collective perspective and understand research processes.^{8–19} They combine experiential expertise and research preparedness. These PRPs are often in close contact with many other types of patients, from the other descriptions included here. In encounters with researchers, they may switch roles, talking about their own experiences and describing collective perspectives and their research knowledge.¹² A few of them have received a formal training as researchers, and are sometimes referred to as ‘patient researchers’.²⁰

We advise researchers to adjust their approaches and procedures to potential patient representatives and consider their needs for information and support.¹² When they are part of the research group, researchers should offer them compensation and authorship (the latter, when criteria for authorship are met).^{21–22}

DISCUSSION

Although patient engagement and involvement has been broadly accepted in some parts of the world (eg, Australia, Canada, parts of Europe and the USA), the approaches for finding patients to be involved in research remain rather unsophisticated. Patients are often invited based on convenience, regardless of their qualities and knowledge. We feel that these stages of adversarial growth will help researchers and patients see what types of perspectives and skills may be needed for a research project or a research team, and hopefully will result in ‘matches’ being made that are appropriate and beneficial to everyone.

People with an individual lived experience (stage 1) can add their naïve and authentic individual experience to research.^{12–23} They do not have a collective patient perspective and provide their individual experiences only.²⁴ Their abilities to join a team or be part of a guideline panel may be very limited. On the other hand, PRPs (stage 4) do have a collective perspective and training that greatly facilitates their abilities to be part of a research team. While some of their own individual experiences (eg, diagnosis and start of treatment) may be recalled from a long time ago, they can also share the experiences and perspectives of other. In the philosophical and sociological literature on patient involvement this is described as a trade-off between authenticity and representativeness.^{12–25–26}

These stages will apply to most people with rheumatic and musculoskeletal diseases engaged in research, but not all. And they may not be strictly consecutive, but sometimes overlapping.^{9–11} People may go back to earlier stages as a result of fluctuating symptoms, or changes in their environment.¹⁸ Often transition to a new stage is facilitated by fellow patients, as ‘mentors’.

The recommendations for matching in [table 2](#) are not meant as strict directives. They may be used by patient organisations as well, to find the best candidates to match researchers’ needs. We believe these stages have face validity, and may also be useful in fields outside of rheumatology.^{4–27} However, we think they would benefit from a more thorough validation in projects and initiatives.

In general, patient involvement is a process of mutual learning for patients and researchers.^{12–28} The authors of this Viewpoint have all progressed through these stages of adversarial growth: a painful, frustrating and sometimes rewarding learning process.^{11–12, 23} We learnt to navigate an environment of power imbalance created by the hierarchy of academia, unfair institutional procedures that were never created specifically for us, and a number of other barriers such as tokenistic situations and even disrespectful communication. Experiential knowledge is often not acknowledged as valuable to scientific research, and experiential expertise may not be viewed as an equal and valuable asset on a research team as, for example, those brought by a biostatistician or a library expert.¹²

In recent years, the authors have all shifted to the role of advisor or consultant in professional capacities, beyond the role of PRP. Although we are still patients and caregivers, we may no longer see ourselves solely as patient partners in research as we are often leading patient engagement initiatives ourselves,²⁹ and helping others and organisations to engage patients in the everyday work they do.^{3–4, 30} This advisor-role may even be seen as a fifth stage—we are seeing more patients move beyond research partners to using their lived experience and education to make a career out of patient engagement.²⁷

While this has been our experience, we are not implying that reaching this or any other stage should be the goal of patient representatives in the context of research. No ‘type’ of patient is more important than others. Regardless of individual qualities and knowledge, we believe that all patients engaged in research have a single goal in common: to contribute to research that ultimately will change the lives of many other patients.

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Competing interests CS is advisor patient involvement in research at the University Medical Center in Utrecht (UMC Utrecht), the Netherlands and at PGOsupport, the Netherlands. He lives with lung sarcoidosis for more than 25 years; his daughter lives with Juvenile Idiopathic Arthritis (JIA) for more than 20 years. CS is volunteer at the Dutch JIA patient and parent organisation (Jeugdremmavereniging; member of ENCA), and a member of the Scientific Advisory Board of the Dutch Lung Foundation. He received no fees from pharmaceutical companies. DPR is founder of Five02 Labs Inc, a consulting firm that provides scientific and patient-focused services. She was diagnosed with rheumatoid arthritis in 2006 and osteoarthritis in 2021. In the past 3 years, Five02 Labs’ clients have included various universities and not-for-profit organisations (eg, Clinical Trials Ontario, CIHR Institute of Musculoskeletal Health and Arthritis (Canada), University Health Network (Toronto), Strategy for Patient Oriented Research’s Chronic Pain Network). Five02 Labs also received fees from and had travel expenses covered by Lilly Canada for participation in an advisory board. DPR is the volunteer vice president of the Canadian Arthritis Patient Alliance, a patient run and led organisation whose activities are largely supported by independent grants from pharmaceutical companies. MdW is convener of the EULAR online course for patient research partners and chair of the EULAR study group for collaborative research. He lives with psoriatic arthritis for more than 40 years. He is volunteer of Stichting Tools, a not-for-profit organisation that provides education and advice regarding collaborative research to patient representatives and researchers. Stichting Tools has received fees for lectures, training and consultancy from PGOsupport (Netherlands) and pharmaceutical companies.

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