The patient will see you now: a new era of empowered people living with health conditions

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This is what you see...
I have so many questions, yet nobody seems to have any answers
Background
A JOURNEY OF OVER 20 YEARS

1996
Diagnosed with juvenile idiopathic arthritis (JIA)

1999
Commenced disease modifying treatment

2004
Commenced biological therapy

2006
Onset of Crohn’s disease

2008
Diagnosed with Crohn’s disease

2012
Diagnosed with fibromyalgia

2017
Here I am…
Arthritis is not just an old person’s disease

- **Juvenile**:
  - Onset before the age of 16

- **Idiopathic**:
  - Unknown cause

- **Arthritis**:
  - One or more inflamed joints

1 in 1000 children have JIA

Up to 17,500 living with JIA

Higher female: male ratio for most sub-types

- **Oligoarticular**
- **Psoriatic**
- **Systemic**
- **Polyarticular** (RF+ or RF-)
- **Undifferentiated**

Arthritis Research UK (2017)
What is a ‘normal’ childhood?

- **Weekly visits** to the hospital
- Polypharmacy
- Negative **side effects** to treatment
- **Absence** from school
- **Exhaustion** in the evenings and at weekends
- **Social isolation**
- Inability to **participate** in contact sports
- **Different** from everybody else
- **Growing up** too fast
Living with a label

- The **patient**
- Talking **about them** whilst they’re in the room
- **We** don’t think they’ll like that
- **They can’t** self-inject, they’re far too young
- **It will** scare **them**
- The **subject** in the study
- It must be such a **burden**
- I saw this **arthritis patient** in clinic today

Simon JIA patient Co-morbid Crohn’s Review in 6/12
DIAGNOSES BECOME MORE LIKE A SHOPPING LIST... AS DO TREATMENTS

- Juvenile idiopathic arthritis (JIA)
- Joint hypermobility
- Psoriatic arthritis (PsA)
- Fibromyalgia
- Chronic widespread pain
- Crohn’s disease
- Irritable bowel syndrome
- Lactose intolerance
- Optic disc drusen
- Psoriasis
- Eczema
- Seasonal rhinitis
- Recurrent sinusitis
- Chronic idiopathic urticaria and angiodema
- Folate deficiency anaemia
- Gastroesophageal reflux disease
- Slipped capital femoral epiphysis

CURRENT TREATMENTS:
- Adalimumab
- Omeprazole
- Cyclizine
- Fexofenadine
- Ranitidine
- Fluticasone
- Mometasone
- Folic acid
- Buscopan
- Algesal
- Hydroxycobalamin
- Tramadol
- Buprenorphine

PREVIOUS TREATMENTS:
- Infliximab
- Etanercept
- Methotrexate
- Sulfasalazine
- Mesalazine
- Hydroxychloroquine
- Diclofenac
- Naproxen
- Ibuprofen
- Corticosteroids
- Buprenorphine
- Amitriptyline
- Domperidone
- Cetirizine
- Among others!
Inconsistency in defining fibromyalgia

Fibro Fibrous tissues such as tendons and ligaments
My Muscles
Algia Pain

A fibromyalgia diagnosis often feels like the last resort diagnosis... when nobody seems to really know what is wrong

Mild PAIN Severe
Tired FATIGUE Walking dead
A little slow FOG Losing it
You wake up to the unknown, every single day

Varying pain
(severity, location, duration)

Fatigue, ranging from tiredness to complete exhaustion

Cognitive disturbances, including a lack of concentration, temporary memory impairment and mixing up words

Clumsiness and dizziness

Sensitivity to changes in weather and to noise, lights and other factors

Headaches, irritable bowel syndrome and other symptoms

“It sometimes feels as though the plug has been pulled!”
How is your arthritis?
Oh great, your inflammatory markers are normal!

How is your fibromyalgia?
It’s probably flared up.

How are the bowels?
Let me know what the Gastro doctor says.
<table>
<thead>
<tr>
<th>Who do you go to for help? Who can you trust?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rheumatologist</strong></td>
</tr>
<tr>
<td>It often feels like they’re the only ones you can go to, but is it beneficial?</td>
</tr>
<tr>
<td><strong>Allied Health Professionals</strong></td>
</tr>
<tr>
<td>Mixed experiences – sometimes helpful, sometimes not</td>
</tr>
<tr>
<td><strong>Neurologist</strong></td>
</tr>
<tr>
<td>May be helpful, but few people are seen by a neurologist</td>
</tr>
<tr>
<td><strong>General Practitioner (GP)</strong></td>
</tr>
<tr>
<td>From experience, it’s a waste of an appointment!</td>
</tr>
<tr>
<td><strong>Support groups</strong></td>
</tr>
<tr>
<td>Great to meet other people, but sometimes can inflame the situation</td>
</tr>
</tbody>
</table>
Fibromyalgia is more common than most of us think

- A European survey of five countries estimated that 2.9% to 4.7% of Europeans are living with fibromyalgia.
- In the UK, this equates to 2 million people.

We also know that many people may be undiagnosed or misdiagnosed, so this number could be even greater!

- Alzheimer’s disease: 1 million
- Multiple sclerosis: 100,000
The challenges of treatment

Treat the symptoms, not the underlying disease
Only because we don’t know enough about it!

**Pharmacological treatments**
- Trial and error
- They can make things worse
- It ends up being your decision

**Non-pharmacological treatments**
- Pain clinic
- Allied health professionals
- Psychological support

**Self-management**
aka.

See how you get on, come back to clinic in 9 months
I don’t want to lose my job
What will they think of me

Anxiety
Guilt
Depression
Isolation
Worry
Judgement
Obsessive

I’m not lazy
Is it all in my head?
Listen to me
Advice that angers me

“"You need to pace yourself. Don’t do too much.""
Realistically, how do you expect a young person striving to develop their career to ‘pace’ themselves?
Self-management
On average, your recorded health data accounts for approximately 10% of your time each year.

Healthcare environment: 10%

At home, whilst studying or in work: 90%

With no objective measure in between!
Occipital neuralgia can cause intense pain that feels like a sharp, jabbing, electric shock in the back of the head and neck. Other symptoms include: Aching, burning, and throbbing pain that typically starts at the base of the head and goes to the scalp. Pain on one or both sides of the head. 13 May 2016

Occipital Neuralgia: Symptoms, Causes, Diagnosis, Treatments, and ...
www.webmd.com/migraines-headaches/occipital-neuralgia-symptoms-causes-treatments

People also ask

- Do tumors on head hurt?
- What does your headache mean?
- Why do I have a headache all the time?
- What causes pain in the back of your head?

Is This A Brain Tumor That Hurts? | MHNI Migraine Headache and ...
www.mhni.com/headache-pain-faq/headaches-brain-tumors
Hip pain
This booklet provides information and answers to your questions about hip pain.

Fibromyalgia Action UK
Fibromyalgia Action UK

Most of us have had flu and suffered aches and pains all over our bodies, and just wanted to sleep until it all goes away.

Imagine feeling like that and professionals not believing you. Wanting to work, look after the family or even just look after yourself and not being able to.

You would want to know why. You would want to know what to do to make things better.

Many people with Fibromyalgia struggle with this for years. It often takes an article in the media to alert them to Fibromyalgia as a possible cause for their many symptoms.

Many health professionals do not have the expertise to diagnose or treat people with Fibromyalgia, but it is estimated that 2% (1 in every 50) of the population are likely to develop this condition, mainly women, but far fewer are likely to be properly diagnosed.
You are not alone. With PatientsLikeMe, you can:

- Share your child’s experiences with an engaged community.
- Find others like your child, or other caregivers like yourself, to help answer the question “Is this normal?”
- Learn more about your child’s journey and health outcomes.
- Discuss health and life issues with a support network of people just like you.
- Improve communications with doctors, nurses, therapists and specialists.
- Advance medical research about autism spectrum disorders.

Join free: www.patientslikeme.com
People with health conditions are keen to use technology to help manage their daily lives

Advancements in technology have enabled health professionals to **better diagnose and treat people** with health conditions.

However, the uptake of technology to enable people with health conditions to better **self-manage their conditions** has been slower and poorly accepted.

With the increased use of **electronic medical records, telehealth services, and mobile technologies**, health professionals, patients and carers are starting to see the benefits that these new medical technologies can bring.

Healthcare Business & Technology, 2015
Using technology for health purposes
Using technology to manage your life
Where’s the evidence?

Rigorous, evidence-based, user-led ‘apps’

Commercial, non-evaluated, independent ‘apps’
Apps and adolescents: a systematic review

Just 4 out of 19 published papers met the criteria of the review.

- Pilot RCT
- Pre-/Post-test studies
- Combined total of 46 participants

Type 1 diabetes, asthma and cancer

More studies with larger groups
Better patient/professional input
Robust evaluation methods

Majeed-Ariss et al. (2015)
Mobile and tablet apps can help you to track your health, as well as connecting you with other people

**Track your health**
- Monitor your symptoms, treatments and questions
- View the small and big picture

**Connect, and learn from others**
- Share experiences
- Give and receive support and guidance
- Feel that you’re not alone
The ins and outs of tracking capabilities using mobile and tablet technology

What do people track?

- Activity
- Food
- Weight
- Sleep
- Mood

The top 5 choices

Why do people track?

<table>
<thead>
<tr>
<th>Motivations</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>To improve health</td>
<td>To cure or manage a condition</td>
</tr>
<tr>
<td></td>
<td>To achieve a goal</td>
</tr>
<tr>
<td></td>
<td>To find triggers</td>
</tr>
<tr>
<td></td>
<td>To answer a question</td>
</tr>
<tr>
<td></td>
<td>To identify relationships</td>
</tr>
<tr>
<td></td>
<td>To execute a treatment plan</td>
</tr>
<tr>
<td></td>
<td>To make better health decisions</td>
</tr>
<tr>
<td></td>
<td>To find balance</td>
</tr>
<tr>
<td>To improve other aspects of life</td>
<td>To maximise work performance</td>
</tr>
<tr>
<td></td>
<td>To be mindful</td>
</tr>
<tr>
<td>To find new life experiences</td>
<td>To satisfy curiosity and have fun</td>
</tr>
<tr>
<td></td>
<td>To explore new things</td>
</tr>
<tr>
<td></td>
<td>To learn something interesting</td>
</tr>
</tbody>
</table>
Young people with childhood-onset arthritis felt that an app would help them to take control of their health.

Your personal diary
Record how you are affected by your condition. Consequently, you will get a better understanding of the different factors that affect your condition.

How is your day?
Record how you feel regarding pain, tiredness, mood and stiffness. You can also use a pain map to pin out specific pain locations.

You remember it all
Choose between written notes, sound files and pictures to document your day. Then you do not have to remember everything yourself.

A great overview
Statistics will show you the connection between your pain, mood and level of energy/activities.

Get the most out of your appointment
Show your rheumatologist how you have been since your last visit.

Peer support
Share tips and advice with other people. For example, use the app to get a helping hand or supportive word.
Case study: RheumaBuddy

- An easy way to keep **track of your everyday life** with a rheumatic or musculoskeletal disease (RMD)
- Developed by an **expert team** of individuals, including digital specialists, health professionals, patient organisations and young people
- RheumaBuddy will be used in clinical trials that serves both the purpose of **clinical evaluation and input for product development**
Case study: Know Your DAS

- Developed by the National Rheumatoid Arthritis Society (NRAS) in the United Kingdom
- Helps you to stay one step ahead of your RA, and can be used to assess how well your treatment is working
- Key features of the app include:
  - Health diary
  - Video guide to patient-assessed joint count
  - ‘Capture your own joint’ camera feature
  - Summary of results reporting tool
  - DAS28 assessment calculator
As well as empowering people to self-manage their health, technology can generate lots of data

- Mobile technology enables the collection and analysis of ‘big data’ for the first time in human history
- **Innovation vs validation**
- Do lengthy, cost-heavy clinical and regulatory evaluations ensure a better digital product?
- It has the potential to collect **large scale, anonymised human behavioural (and biological) data** across cities, countries and continents
- This could and should influence decision making processes by governments, regulatory bodies and healthcare providers – making more informed decisions with better potential outcomes
Challenges we face using innovative technologies to enhance disease self-management

- Tracking too many things
- Not tracking triggers and the context (which may need additional sensors)
- Lack of appropriate tools for data analysis and visualisation
- Lack of scientific rigor on data analysis, leading to misleading interpretations
- Sustained usage and user motivation
- Policies and processes
- Personalisation
Research journey
Research is a unique, challenging but exciting journey... as is your involvement in research.

November 2012
Appointment to the Clinical Studies Group

December 2013
Invitation to national digital technology project

October 2014

December 2015
1st journal article

February 2017
Invitation to International collaboration

November 2016
2nd journal article
Getting involved in the paediatric rheumatology clinical studies group

What’s my role amongst these experts?
Why must patients, parents and carers be involved in research?

People who are affected by research have a right to have a say in what and how research is undertaken.

*Health care professionals and researchers must not assume that they know more than anyone else… we should recognise that other people are experts in their own right and accept that other people have skills that will enrich the quality of research.*

▷ Involvement can facilitate **recruitment** to research studies
▷ Involvement can enhance the **study design** to ensure it is the most suitable approach for patients and their families
▷ Involvement can raise the research **quality** and long-term **cost-effectiveness**
▷ Involvement can raise **expectations**, and consequent **satisfaction** with research
▷ Most importantly, involvement can make research more relevant – it is everyone’s business!
Delivering research to make patients, and the NHS, better

Take part in research
- GPs, consultants, AHPs and nurses signposting patients and carers to research studies
- Local NHS Trust hospital or GP surgery website
- UK Clinical Trials Gateway
- Local NIHR Clinical Research Network
- Join Dementia Research

Learn about research
- Online courses
- Patient stories
- News
- Social media

Helping to shape research
- Patient Research Ambassador
- Patient Participation Groups
- Clinical Studies Groups
- Advisory Panels
Patient, parent and carers must be involved in every step of the research process

- Patients, parents and carers can contribute to all aspects of research, including:
  - Identifying and prioritising research topics;
  - Developing a grant application alongside professionals;
  - Designing and managing research;
  - Undertaking the research;
  - Analysing research data;
  - Disseminating research findings.

![Research cycle diagram](image)
Challenges of patient, parent and carer involvement in research

- Ensuring that patient, parent and carer priorities are addressed
- **Representing the wider community**, not just personal views
- **Confidence** building and mentoring
- Education and **training** about research and health care
- Financial support and out-of-pocket **expenses**
- Managing **expectations** of everyone involved
- Managing **conflicts** and personal **opinions**
- Awareness of **time, energy and commitment**
Involving patients, parents and carer advocates will help the entire research team to:

- Find out about research questions that are important to people living with ill health
- Learn new ideas for innovative and novel approaches to conducting research
- Understand how best to approach and research participants
- Find new ways to talk and communicate with patients, parents and carers
- Produce material that is clear and easy to understand for everyone
Exemplar activities of patient, parent and carer advocates (PPCA) working with researchers

- Bi-annual physical meetings
- Monthly virtual meetings
- Quarterly PPCA meetings
- Consultation activities
- Prioritisation exercises
- Guidance developments

Research collaborators

- European recommendations for transitional care (paediatrics/adults)
- Mobile apps for rheumatic diseases
- Outcome measure studies
- Steroid induction regimen in JIA

Comment on materials

- Grant applications
- Study protocols and design
- Participant information sheets
- Abstracts and lay summaries
- Discussion and interview guides
- Evaluation and dissemination
Co-production and collaboration, as equal partners, is the key to unlocking success.

- **Patients, parents and carers**
- **Health care professionals**
- **Societies and NGOs**
- **Researchers**
- **Patient Charities**
The top concerns of young people living with childhood-onset arthritis

- Most young people with childhood-onset arthritis commence treatment with the antimetabolite, Methotrexate
- In consumer-led surveys with young people, **tolerability** of Methotrexate remains one of the highest priorities
- Young people and parents report that it has impacted on physical and psychological health
- As consumer representatives, we are now co-applicants on a study that was informed by this research to address some of these challenges
  - Administration of anti-emetic before treatment, learning from paediatric oncology
  - This makes sense – it is cost-effective and efficacious when tolerated (and adhered to!)
Research has empowered me to take better control of my health

- Learning about my conditions
- Treatment discovery and management
- Peer support
- Empowerment
- Developing self-management
- Skills and confidence development
Understanding the patient’s journey

When is it the right time to get involved in research?
Be proactive
Generation R
young people improving Research

http://generationr.org.uk/
Patient Research Ambassador Initiative
Putting people at the heart of research

- An emerging initiative, as part of the NIHR’s commitment to involving more people in research
- Anyone who is passionate about involving patients and their families in research
  - Participation
  - Engagement
  - Involvement

https://www.nihr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/
NIHR CRN: Children

• 14 Clinical Studies Groups (CSGs)
  • Allergy, Infection and Immunity
  • Anaesthesia, Intensive Care and Cardiology
  • Cleft and Craniofacial Anomalies
  • Diabetes and Endocrine
  • Gastroenterology, Hepatology and Nutrition
  • General Paediatric
  • Inherited Metabolic Disorders
  • Neonatal
  • Nephrology
  • Neurosciences
  • Pain and Palliative Care
  • Pharmacy and Pharmacology
  • Respiratory and Cystic Fibrosis
  • Rheumatology

http://www.crn.nihr.ac.uk/children/about-children-research/clinical-studies-groups/
GenerationR
• Young Person Advisory Groups
  • Birmingham
  • Bristol
  • Liverpool
  • London
  • Nottingham
  • Mental Health Group

http://generationr.org.uk/

INVOLVE
• Support active public involvement in NHS, public health and social care research
  • People in Research tool
  • Advice for best practice involvement

iCAN

- iCAN is a worldwide consortium of children's advisory groups working together to provide a voice for children and families in health, medicine, research, and innovation through synergy, communication and collaboration
  - KIDS Barcelona
  - KIDS Central Ohio
  - KIDS Chicago
  - KIDS Connecticut
  - KIDS France
  - KIDS Georgia
  - KIDS Houston
  - KIDS Kansas City
  - KIDS Michigan
  - KIDS Sydney
  - KIDS Utah
  - KidsCan (Vancouver)
  - ScotCRN Young Persons Group (Scotland)
  - Generation R (England)
  - eYPAGnet (Europe)

http://www.icanresearch.org/
Patient Research Ambassador Initiative

Royal College of Paediatrics and Child Health &Us

North West People in Research Forum

European League Against Rheumatism

Disease specific charities and other non-governmental organisations
Remember that iceberg?
Here’s what you didn’t see...

- Chronic pain
- Hair loss
- Insomnia
- Anxiety
- Organ damage
- Depression
- Isolation
- Rashes
- Fevers
- Headaches
- Fatigue
- Brain fog
What you might see vs what you don’t see

- Bright smile
- Confident
- Fashion sense
- Care free
- Happy

- Depression and anxiety
- Sleepless nights
- Infusion wounds
- Injection bruises
- Medical supplies
- Joint pain and fatigue
Thanks for your time today. Please ask questions!

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