



Artwork by Tony Pickering

# "Patient, Heal Thyself"

Patient-orientated  
conference

Developed by members of the  
European Health Innovation  
Collaborative (EuHIC)

16th May, 2019

London

St Giles-in-the-Fields Church  
and the Vestry House

## CONFERENCE REPORT

„A reminder to all: the world is changed by your example, not by your opinion.“

-Trishna Bharadia on the importance of creating an active patient community

The second patient-orientated conference entitled 'Patient, Heal Thyself,' was held at St Giles-in-the-Fields Church and Vestry House, Covent Garden, London, on Thursday 16th May, 2019. This intensive 1-day event involved a series of presentations from patients, healthcare professionals, academics, health writers and industry representatives. Our two eminent conference chairs were Emma Kinloch (Chair of the National Cancer Research Institute Consumer Forum, UK) and Dr Adrian Tookman (Clinical Director, Marie Curie UK).

Session leads included Dr Tessa Richards (Editor, BMJ) and Professor Andrew Krentz (University of Reading). The keynote address was provided by well-known patient advocate, writer and broadcaster, Trishna Bharadia. The day was rounded off by a relaxed jazz and canape networking event.



St Giles-in-the-Fields Church , Photo by Sam Waldron



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**Dr Adrian Tookman** (London): Clinical Director for Marie Curie UK and Medical Director at Eaton Hall

**Prof. Annie Cushing** (London): Professor of Communication Skills and Head of Clinical Communication and Learning Skills Unit, Queen Mary University

**Dr Carolina Rojido** (Toulouse): Medical Doctor, Scientific Writer specialising in oncology and nutrition

**Colleen Shannon** (London): Freelance healthcare writer and journalist

**Emma Kinloch** (London): Chair of the National Cancer Research Institute Consumer Forum

**Dr Faye Gishen** (London): Associate Head at University College London Medical School

**Gerry Harris** (London): Health Mentor Programme Coordinator Queen Mary University

**Chris Carrigan** (Leeds): Researcher at Leeds Institute for Data Analytics at University of Leeds

**Grace Ogden** (London): Campaigns and Public Affairs Officer, The Royal College of General Practitioners

**Graham Armitage** (Newcastle): Co-founder of VOICE and Operations Director of the National Innovation Centre for Ageing

**John Marsh** (London): Patient advocate at useMYdata.org

**Nigel Penny** (Coventry): Head of Health and Life Sciences at CU Coventry and Director of the British Association for Nutrition and Lifestyle Medicine

**Rachel Jury** (Bournemouth): Founder of rocking2stomas

**Dr Robina Shah** (Manchester): Chartered Consultant Psychologist, Honorary Fellow of the Royal College of General Practitioners and High Sheriff of Manchester

**Simon Lord** (Oxfordshire): former cancer patient, personal trainer and health activist

**Simon Page** (Cambridge): Global Publications and Communications Manager for Neurosciences at Ipsen

**Stephanie Nimmo** (London): Writer, journalist, campaigner and blogger

**Trishna Bharadia** (Maidenhead): Patient engagement consultant; Ambassador for MS Society UK; ADD International; Sue Ryder Patron for Huntingdon, Peterborough & Cambridge MS Therapy Centre and ParaDance UK

**Tony Pickering** (London): Medical artist, illustrator, designer and graphic novelist

## Patient heal thyself: How can you improve your treatment?

**Simon Lord** was diagnosed with prostate cancer at a young age and spoke with passion about his experiences. He questioned whether healthcare is being done to us rather than with us. Patients worry about their next appointment and the information they are provided. Also, many may not remember what went on during their appointment, as a result, they leave the consultation with mixed messages. Patients are all too often told what not to do rather than what to do.

Primary healthcare is under a huge amount of pressure to deliver what it can't deliver. One example is prehab (prehabilitation). Once management has been agreed, patients cannot do much to improve their actual treatment. However, through prehab they can prepare their bodies and minds to better cope with treatment. Prehab usually involves a range of interventions, notably discussions around improving diet and physical activity. Research has shown that just two weeks of prehab can greatly improve outcomes. Simon advocates prehab for all suitable patients.



Simon Lord, Photo by Sam Waldron

### Conference Summary

- support the **active role of patients** during the treatment process
- encourage doctors, carers and relatives to **listen** to patients' experiences
- encourage doctors to reflect on **patient perspective**
- utilize **digital communication** for patient care
- foster **integrated medicine** and **evidence-based health care**



## Hacking your health: How will technology empower patients?

There have been exciting developments in genomics, artificial intelligence (AI) and digital medicine in recent times. **Grace Ogden** discussed how new technologies can assist GPs in improving patient care. Her presentation was based on an extensive consultation exercise that sought the views of GPs and patient groups.

New technology needs to:

- Protect personal data
- Create more time for healthcare professionals (HCPs) to enrich the interactions they have with their patients
- Empower patients to better manage their own health
- Support continuity of care and ensure patient safety
- Help tackle health inequalities by addressing the needs of deprived communities and vulnerable groups
- Engage GPs and GP trainees in the innovation and development process
- Be effectively integrated and scalable to strengthen the quality and efficiency of NHS services
- Be underpinned by research and robust evidence-based evaluations
- Provide information that is reliable, sufficiently comprehensive and regularly reviewed by experts
- Support GPs and the wider practice team in monitoring population health data to provide tailored proactive and preventative care
- Improve care for 1 in 4 people in England living with multiple long-term conditions

New technology must be cost-effective. Success will likely depend on appropriate training. Patients may also need support in navigating new systems.

Half of modern GP practices are not fit for purpose. To be effective, modern GP practices must be digitally enabled with interoperable IT systems and secure, reliable broadband. They need to have access to a single shared electronic patient record system that can document a patient's interactions across the whole health system.

## The challenges of a rare diagnosis

**Emma Kinloch** discussed the challenges of preventing rare diseases in the absence of known risk factors. Such diseases may be difficult to diagnose because of their symptom profile, unrecognized appearance on scans and unusual features on histological examination.

There are many challenges when it comes to treatment:

- Diagnosis is often delayed, resulting in the need for more radical treatments
- For some patients, delay may mean the disease becoming incurable. In the case of a tumour, the lesion may be inoperable or require more extensive surgery
- Radical surgery could necessitate extensive reconstruction or the need for a prosthesis
- Guidance as to the optimum treatment regimens, duration and follow-up may be lacking. For some diseases, there are no known treatments
- In the case of rare tumours, there is limited knowledge as to the benefits and risks of radiotherapy or chemotherapy
- The number of clinicians with experience in managing a rare disease may be low
- Patients may require ongoing monitoring for many years
- Limited patient numbers and a lack of interest from industry and funding bodies hinder research

Patients with a rare disease diagnosis would benefit from:

- Expanding collaborations between clinicians, researchers and patients
- Raising awareness e.g. host in-person meetings, organising patient – research trial discussion days
- Encouraging researchers and funding bodies and lobbying for new treatments to be available



## The changing face of palliative care

**Dr Adrian Tookman** Palliative care is the support of people with advanced, progressive life limiting diseases. The focus is on controlling symptoms rather than curing.

There are three different types of disease trajectory:

- A very short time period of health decline before death e.g. cancer
- Long term limitations with intermittent exacerbations and sudden death e.g. organ failure
- Prolonged deterioration before death e.g. frailty or dementia

The survival rates for those diagnosed with cancer have significantly increased since 1970.

1 in 3 babies born today will live to 100. There are, however, consequences of prolonged survival: added years may be plagued by new illnesses, pain and disability.

The UK is the best place to die according to the end-of-life care index. Overall life expectancy has been increasing since 1980; however, life expectancy for those with a serious illness has been increasing at a faster rate due to care improvements.

It is important to understand the changing nature of healthcare and respond appropriately. The downside of modern specialist medicine is a focus on one facet of the patient's health. Now is the time to challenge established views on optimum management of people living with an advanced, progressive, life limiting illnesses. Improved symptom control, holistic care, sensitive and honest communication, dignity, hope and a feeling of being in control are most important to the patient.

Good communication is essential. A fresh approach that encourages open and honest conversations is required. Developing trust is key, for example, by asking patients what they want rather than telling them what they need. HCPs must understand, acknowledge and address the spectrum of uncertainty and offer more personalised care.



Dr Robina Shah , Photo by Sam Waldron

## The Community Healthcare Conundrum

**Dr Robina Shah** spoke about patient communication. The present care system is complex. Often, the patient's health is not well explained, or they choose not to understand it. When patients are diagnosed, some take the diagnosis on the chin, some walk away and ignore it, and some come back to it later.

In recent years, hospitals have significantly improved patient communication. For example, doctors and hospitals increasingly pay attention to the impact of the diagnosis on the individual patient and the patient's family relationships.

Successful health and social care is all about rapid and appropriate response to an individual's needs. But for that to happen, the patient needs to feel engaged and be willing to participate. It is important for HCPs to promote different forms of physical activity to improve the patient's wellbeing. Similarly, the community needs to come together to assist and support patients during their treatment and recovery process.

„Developing trust is key, for example, by asking patients what they want rather than telling them what they need.“

- Adrian Tookman on palliative care

„Patients like to feel involved. There are genuine roles for patients in supporting research and publications.“

- Simon Page on improving patient communication

### VOICE: Improving patient involvement in research

VOICE ((Valuing Our Intellectual Capital & Experience), founded in 2007, is a successful citizen involvement network and digital platform that promotes dialogue between researchers and the public. **Graham Armitage** told us more about VOICE and its mission. VOICE supports idea development and set research and innovation agendas based on identified needs and citizen priorities.

Registration and setting up interest and notification preferences is straightforward. Patients can browse a wide range of content and can register to participate in events, complete questionnaires or join a special interest group. They are also able to receive feedback on projects and can take part in online discussions with researchers and other VOICE members.

VOICE offers a thriving digital platform linking research and innovation savvy citizens that allows participants to control their involvement. VOICE provides an opportunity for researchers to connect with relevant collaborators. Activities might include research projects, workshops, focus groups, steering groups, and participating in surveys and polls. Researchers can also share support and learning resources to encourage patient involvement.



Photo by Sam Waldron



Prof. Andrew Krentz, Photo by Sam Waldron

### How can we work with patients, for patients? An industry perspective

In general, patients who are better informed and empowered feel less worried and more positive, meaning they have a better quality of life and are more likely to make good healthcare decisions. **Simon Page** discussed various approaches to improving patient communication. One approach would be to make all healthcare publications open access. This would widen their impact, facilitate sharing and allow for greater transparency and trust. Additionally, publications should always include lay summaries providing a brief overview of the study and explanations of complex concepts and scientific terms for the lay person. This would support discussions between HCPs and patients.

Patients like to feel involved. There are genuine roles for patients in supporting research and publications. Examples include participation in advisory boards and joining publication steering committees. Patients are increasingly contributing as authors, manuscript reviewers and writers of lay summaries. They may also be well-placed to assess the value of publications, help design future studies and advise how on data communication for maximum impact.

### Patient nutrition: You are what you eat

**Dr. Carolina Rojido** and **Nigel Penny** reminded the audience: eating a balanced diet is important; however, most people struggle to attain this. In high income countries, the number 1 cause of death is ischaemic heart disease (IHD), which is usually linked to poor diet. Globally in 2016, there were 145 deaths for every 100,000 people as a result of IHD.

Red and processed meats raise the risk of some tumours e.g. colorectal cancer. High fat intake is associated with cancer recurrence and early mortality in women with breast cancer. Similarly, a cholesterol-rich diet appears to be carcinogenic and encourages cognitive decline and dementia.

Many societies rely entirely on vegan diets that exclude all animal products. A vegan diet can help prevent and treat many diseases by reducing blood pressure and cholesterol levels. Veganism increases the metabolic rate and promotes weight loss. There is also a beneficial effect on inflammation, which decreases the chance of dementia, arthritis, cancer, diabetes and cardiovascular disease. Indeed, these societies have life spans that are up to 10 years longer than the global average, whilst also having the lowest middle age mortality rates.

However, many processed vegan foods are overwhelmingly made up of highly refined fats and carbohydrates derived from nutrient depleted plant fragments. They generally lack fiber, vitamins and minerals, and contain artificial sweeteners, preservatives, colors and flavors.



Photo by Steven Walker

### Sex and disability - still a taboo in healthcare?

Sex is becoming less and less taboo. Why, then, are disabled people consistently excluded from the conversation? **Rachel Jury** explained that people with disabilities have the right to sexual expression. She added that healthcare professionals often feel uncomfortable talking about sex with disabled people as they are concerned about stepping over the line and offending the patient.

Sexual Health and Disability Alliance (SHADA) is an organization set up to bring together employed professionals who work with disabled people in health, education and therapeutic practices. SHADA envisages a more inclusive society where every disabled person's unique sexual identity is given due respectful, non-judgemental recognition and acceptance, enabling its diverse expression and celebration. Its mission is to support and facilitate the sex and relationship needs of all people with disabilities, campaigning to remove the stigma attached with sex and disability.

„Sex is becoming less and less taboo. Why, then, are disabled people consistently excluded from the conversation?“

- Rachel Jury on sex and disability

## Enabling patients through art

**Tony Pickering** explored how art and comics have helped him cope with type 1 Diabetes and can provide support for diverse groups. He considered the following topics:

- Understanding information — successful communication involves overlapping images, sound and conceptualisation. This is enhanced by adding weight and detail to examples encountered in daily life
- Visualizing a disease — this can support a patient in successfully navigating through their illness and help explain new experiences. Here, little everyday-things matter
- Better understand situations — illustrating two or more versions of their potential future journey can aid patients with their decision-making
- Balancing life and medicines — most patients have little idea of how their disease and treatment journey will impact their lives. Illustrations may provide some insight into how they might feel
- Creating knowledge — the patient's experience of their disease and treatment matters. This information is of value to other patients, HCPs and industry. Appropriate images can create a relationship with research
- Inspiration and empathy in image — this can comfort and help patients better manage their disease



"What's Happening", Artwork by Tony Pickering



Grace Ogden, Photo by Sam Waldron

## Patient mentors: How are they enhancing their own treatment?

**Prof. Annie Cushing** and **Gerry Harris** explained that patient centred care requires full understanding from both the doctor and patient around treatment options; likely outcomes; and patient background, circumstances and aspirations. The key to enhancing treatment is communication. Some patients wish to seek second opinions or additional information about their disease and treatment. HCPs have a duty to provide reliable signposting.

Maintaining autonomy is important. Those affected by illness need to be able to make the final decision regarding their treatment. However, the knowledge gap between doctor and patient can undermine their decision-making power.

It is important that the information provided is balanced and doesn't give false hope. Worry and confusion are exacerbated by undue negativity and optimism. Clarity and accuracy are key.

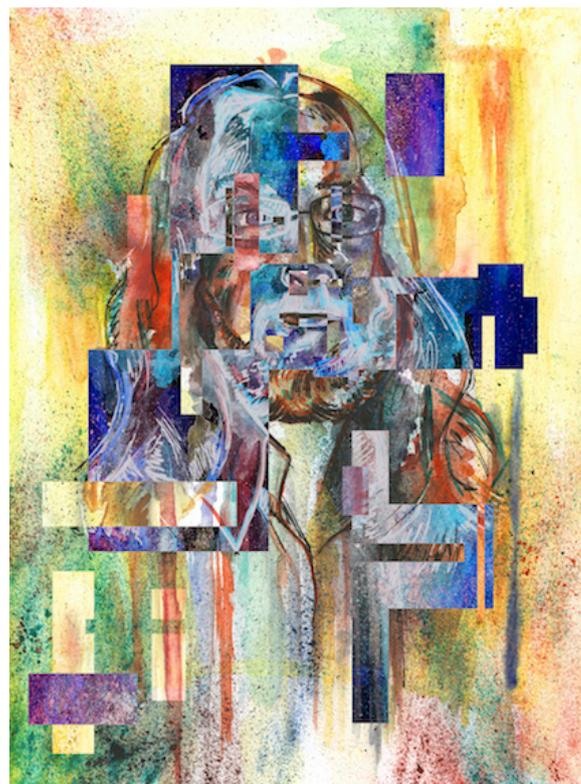
Sharing health information is central to informed decision making. Healthy dialogue between patient and doctor increases understanding and decrease fear and prejudice. It is important that the patient understands what is wrong with them, their current situation and what the future holds.

## Saving lives and improving treatment: Why sharing patient data is good

**Chris Carrigan** and **John Marsh** explained how sharing patient data can improve treatment. Use My Data is a movement of patients, carers and relatives. It supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

Many patients are uncomfortable about having their personal information stored in a central repository and fear misuse. Consequently, they increasingly opt out which results in valuable information being lost to data analysts, researchers and clinicians to the detriment of health research initiatives. For example, patients providing data on their cancer experience helps researchers improve treatment. Without such information, legitimate research may be delayed or abandoned. It is hoped that by communicating the value of sharing data the team at Use My Data can change this view.

Our ability to embrace the data challenge is supported by ongoing advances made in technology and data analysis. The biggest risk of failure is through lack of patient and public engagement, support, confidence, understanding, control and trust.



"Anxiety", Artwork by Tony Pickering



Simon Lord, Photo by Sam Waldron

## Let's talk genuine communication in healthcare

**Stephanie Nimmo** began the session by describing her experiences and interactions with HCPs whilst caring for her dying child. She highlighted some major communication failings

**Dr Faye Gishen** and **Colleen Shannon** explained how updated medical school curricula are hoping to address some of these issues:

- Updated model of best practice and clear focus on clinical communication in undergraduate medical training
- Defining the underpinning values, core components and skills required in delivery of contemporary medical care
- Putting patients at the center of consultations
- Increased focus on patient safety, the professional duty of candour and digital medicine



Trishna Bharadia, Photo by Sam Waldron

## The future patient: Empowered, informed, a partner in healthcare

### Keynote address by Trishna Bharadia

Seventy percent of physicians say patient engagement is a top priority. An engaged patient often has better outcomes - this is essential when the healthcare environment is becoming increasingly value-based.

It is important to create an active patient community in order to improve access to support and services for patients. The goal of a patient community is to create awareness and to educate the wider community about the impact of diseases on people's lives.

Why we make the case for shared decision making:

- Better outcomes
- Improved health literacy
- Patient feels in control
- Better HCP–patient relationships
- Enables development of personalised healthcare plans

How can we improve shared decision making?

- Better education for HCPs
- Avoid patient information overload
- Create the right environment in clinics and hospitals

**A reminder to all: the world is changed by your example, not by your opinion.**



## Thanks

We are grateful to our two conference chairs, Emma Kinloch (Chair of the National Cancer Research Institute Consumer Forum, UK) and Dr Adrian Tookman (Clinical Director, Marie Curie UK) and our amazing session leads, notably Dr Tessa Richards (Editor, BMJ) and Professor Andrew Krentz (University of Reading).

Feedback from last year's event highlighted that holding a conference dedicated to patient issues without external influences contributed to better understanding among healthcare stakeholders.

Participants encouraged us to develop this further conference and our sister event in Berlin. Two supporters of note were Richard Stephens (all-round patient champion and journal editor) and Achim Kautz (Deutsche Leberhilfe). We are most grateful.

The meeting could not have happened without the generous support of Alan Carr (Rector, St Giles Church) and Debbie Westerby (Church Manager).

Follow the link to a video documenting the highlights of the conference:  
<https://www.youtube.com/watch?v=211TJOIAiUc>

**We welcome your feedback!**

**If you have suggestions and questions or simply want to say hello, stay in touch!**

**We love to hear from you.**

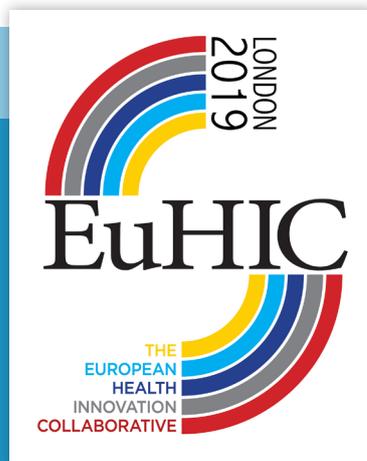
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**Dr Giles**



Look out for our next patient-orientated conference in **May 2020.**

All suggestions for topics and speakers are welcome.

**[www.euhic.com](http://www.euhic.com)**

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