

# “No longer a passenger - being prepared for future patient navigated Medical Records”

## Stories and adventures of modern digital pioneering patients.



# No Longer passengers...



**.Three patient stories from the UK :**

**.Oliver**



**Steve**



**“A”**



**And: UK General Medical Council’s “Decision making  
. and Consent”**

# No longer passengers...

**Oliver Crowton, Builder  
and Developer, Glossop  
Derbyshire, England**



# No longer passengers...



## Oliver Crowton

Good afternoon, my name is Oliver, I am builder with a chronic disease (Ulcerative Colitis) that I have lived with for the last 8 or so years. A couple of years ago, when I was working on Dr Fitton's house, I told him about accessing my medical records. Dr Fitton asked me to read the British Medical Journal (BMJ) Editorial entitled "Implementing person centred approaches". This was published on September 2017 and Dr Fitton asked me to consider writing a response to the article. I did write and the BMJ published my response.



# No longer passengers...

**BMJ Sept 2017 “Implementing person centred approaches”.**

“I am aware, to an extent, of the pressures facing the NHS and the medical profession. These are only what I see in the hospitals that I visit and hear through mainstream media channels, but they are enough to understand that to succeed the system needs to evolve and I think that the person centred care approach is a positive step.

“It is encouraging to hear of building communication and relationships between healthcare professionals and the people receiving care as this can surely only serve to improve engagement and mutual understanding, by this I mean the healthcare professional’s understanding of the patient and the patient’s understanding of their condition or treatment.



# No longer passengers...



“I feel that the ability to share data is an extremely valuable tool. I refer not only to the appropriate and controlled sharing of patient data within and across relevant organisations, which has its own merits, but also and importantly the sharing of patient data directly with the patient to which it relates.

“During the years following my own diagnosis my relationship with my healthcare professionals (doctors, nurses and consultants) has quite suddenly and accidentally become more ‘patient centred’.

“Five years ago I was at a stage in my understanding of my condition and treatment that was so limited it placed the entire weight of responsibility for my care on the doctors treating my condition. At that point in time I had lived with my diagnosis for three years and I was a passenger, along for the ride feeling I did not have a part to play.



# No longer passengers...



“Quite by chance I was then offered the opportunity to sign up for digital access to my records through a portal called ‘Patient Access’ by EMIS.

- I have found that access to my medical data, including test results, consultation details, diagnosis history etc. has empowered me as a patient and given me a platform for meaningful two-way communication with my healthcare professional:
- I ask questions, discuss options for treatment and associated side effects, as well as assisting with the management of my regular scheduled treatments.
- I am able to feel a better level of care with less contact with the surgery.



# No longer passengers...



- I can manage prescriptions and view test results without the need to take up time talking to the surgery staff.
- I can review treatment dates to ensure that my blood tests and treatments are scheduled appropriately without the stress of wondering when they are due.

“In short the access to digital records has allowed me to take some ownership of my condition and work pro-actively with my various healthcare professionals in the management of my disease and its treatment both short and long term.

“I have no doubt that I would not have had the confidence required to begin discussions with my doctors without the access to my records as a basis for communication.





# No longer passengers...



“I find the now annual visits to my Consultant at hospital are also far more useful. I am able to discuss the results of my GP surgery visits and test results and draw directly on them at the consultation from my smartphone if required, adding depth to our discussions.

“In short I am no longer a passenger, I am now very much part of the management team for the effective treatment of my condition and I am pleased to say that I am managing to remain in good health.

“I understand that not everyone will have the capacity to use their data in this way but there are very many who will and I can see access to patient data being a very powerful tool indeed in achieving patient centred care.



# No longer passengers...



•Steve Grieg' story told by Steve

“a patient, an MP {member of parliament} and a reluctant GP”



# No longer passengers...



I had heard that here in the United Kingdom patients should, by law, have access to their full medical records. However, I was not able to access my records. When I contacted my primary care provider or General Practitioner they were very unhelpful. It was only when my Member of Parliament intervened on my behalf that my General Practitioner enabled me to access my records.



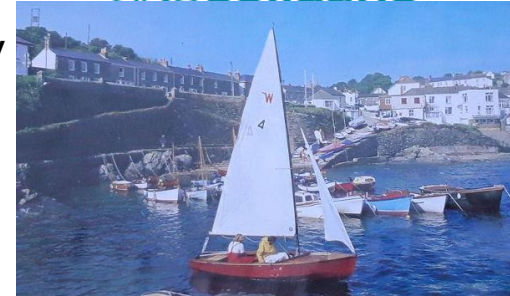
I would like to say this was the end of my concerns. However, in order to access my medical records and other health services I have to use proprietary software which requires me to accept the terms and conditions of the company that provides them.



# No longer passengers...



I would be very much more happy for data about me to be handled by Libre (also known as Open Source) software which has terms and conditions which are shorter, easier to understand and far more attractive to the user amongst other advantages. It is clear that many of us are accepting terms and conditions for computer resources not because we have read and understood and agreed with them but because we need to use the software. It is particularly sad when we do this in relation to our health care.



It may be that agreements with software providers could be limited to the health care providers and the patients might not need to enter into that relationship with the software providers.



# No longer passengers...

That might be an improvement but there is no reason to think that many of the health care providers are any happier to enter into complex agreements than where there is little choice other than to sign up if you want to continue working.

As the data we are discussing is about patients and the processing of the data is paid for by patients through their taxes surely their interests should be given the highest priority.

I think now would be a great time for Libre software health care solutions to be proposed to the UK government firstly because of the amazing success of some Libre software in other fields but also because the UK government did choose a Libre software license for their Covid19 tracing app which shows they do not object in principle to the idea.



# No longer passengers...



## Steve Grieg' story told by Steve

### Thank you for your time.



# No longer passengers...



## A's story

Abigail has “Cerebral Palsy  
Spastic Quadriplegia”.



## No longer passengers...

A's records are shared with other professionals:

School special educational needs coordinator, community paediatrician, physiotherapist, occupational therapist, orthotics, wheel chair service, upper limbs specialist, and more.....





## No longer passengers...



A's mother used on line access to A's GP record to correct discrepancies and inaccuracies in her daughter's record.



# No longer passengers...



As mother found many problems missing:

Severe mobility issues

wheelchair use

Crawling for mobility around the house,

Can not sustain kneeling for long periods



# No longer passengers...



GMC “Decision Making and consent” 9<sup>th</sup> November 2020

UK General Medical Council regulates doctors

Patients need full information to give full consent



## No longer passengers...



“Give patients the information they want or need in a way they can understand”.

“If you delay sharing information.. let the patient know ...share the information as soon as it’s appropriate to do so.”



# No longer passengers...



“You should not withhold information a patient needs

“You may feel that sharing information with a patient would cause them “serious harm” ... it may be appropriate to withhold it.



# No longer passengers...



“‘Serious harm’ means more than that the patient might become upset, decide to refuse treatment, or choose an alternative.”

“You should seek legal advice if you are considering withholding information from a patient.”



No longer passengers...



have a great conference and thank  
you or inviting us

Oliver, Steve, A and Richard