

A toolkit for sustainable single speciality services

Networked care

St Luke's Community Centre

Hello & Welcome to you all!

Here's to absent friends & their future involvement

We are Pioneers! Why we're here? to harness the energy + ideas of patients?

2016 What's been your highlight this year?

My New Eye! Being involved in studies like this!

THIS WILL BE SHARED NATIONALLY you will all be national Superstars!

Irene's STORY PATIENT INFO LEAFLET

2011 - Diagnosed with a very rare disease caused by an ameba transferred by contact lenses + water

I decided to spread the word!

Getting together with OTHER PATIENTS was amazing!

How can I help? What can WE do? we've ALL been given misinformation

Let's write this together!

Thank you for SHARING

John's STORY Buddy System in Ocular Prosthetics

I HOPE I've HELPED patients!

I help patients understand their situation + allay anxiety

PLEASE TELL all YOUR FRIENDS ABOUT IT: IT'S A REALLY GOOD IDEA!

Working With Patients for a Brighter Future

CREATING A VISION TOGETHER

& using these three lenses...: CLINICAL RESEARCH EDUCATION

PATIENTS ARE UP FOR ANYTHING!

FORMING PARTNERSHIPS

I NO LONGER FEEL ALONE

Andrew's STORY GLAUCOMA Seminars St Anne's Hospital

We want MORE INFO! & I want to be MORE ENGAGED!

Andrew's STORY BIRDSHOT VENTUS SOCIETY FOUNDER

2002 I was IN SHOCK when I was diagnosed

2009 went to a Symposium in the U.S. Came home + GOT PROACTIVE: website / leaflets / set up a Society & The Birdshot day was created

OUR GOAL! We organise clay pigeon shoots & other Fundraisers... we raise money

THIS FEEDS INTO RESEARCH

It's gone GLOBAL

Valerie + Carol's STORY Patient as Teacher Education Sessions

We invite patients in, to tell their stories to medical students

insightful How they found it!

I'm an individual! my feelings are just mine!

POSITIVE EXPERIENCE I felt so good afterwards!

& OUR LEARNINGS... what were the:

The sharing of data was vital

creating links!

sharing patient stories

forming a movement!

feeling motivated to ACT!

Patients are highly motivated + engaged!

forming a network: vital

THINGS THAT GOT IN THE WAY

UNUSUAL ACTIONS OF PATIENTS

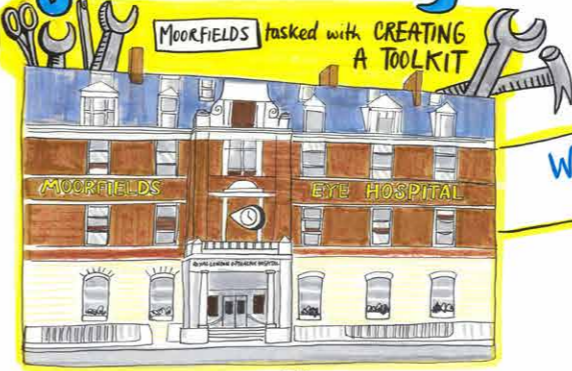
UNUSUAL ACTIONS OF HOSPITAL STAFF!

Particularly useful to people with rare diseases & inspiring them inspires others!

Engagement of clinicians was also surprising

How do we make it EASY to find the information?

It's also a question of **attitudes** to accept that patients have something to SAY A CULTURAL SHIFT



Moorfields tasked with CREATING A TOOLKIT

FROM: CLINICAL TO: HOLISTIC

CHANGING MINDSETS

US+THEM WORKING TOGETHER

ISOLATION TO INTEGRATION

On Monday What will you take into your role?

I'm not going to let this go!

The CEO + CEO will be here next time!

I'm going to spread the word!

I'm going to get patients involved in leaflet creation!

I'm going to speak less + listen more! & think about WHO ELSE should be in this room!

In my teaching I'm going to be starting with the patient!

What will you be doing differently?

We need to work together as charities

COMPLIMENT each other

Patients at the STARTING POINT of everything we do!

it will also save money!

I'm going to encourage the hospital to formally train volunteers.

I'm going to start applying this within our education system: change things with junior staff

we will be sharing all of this!

Thank you to you all for coming!

a spirit that everyone is learning together!

What would Moorfields look like in 5yrs time if we changed the Mindset?

& how could we make sure this happened across the network?

RESEARCH When people visit hospitals

CLINICAL Written info

EDUCATION Patients involved in weekly training

ADAPT A CLINICIAN More visually impaired staff at hospitals

RECEPTION Open to patients as well as clinicians

LIBRARY

CONSISTENT OUTCOME MEASURES Formal & informal spaces to share & network

innovation centres either physical or virtual

CLINICAL all created in COLLABORATION with patients

FB GROUPS! Send emails to ask patients to get involved

make it visible So that everyone can get involved!

More patient authors please!

have these regularly!

More patient authors please!

make the environment welcoming...

where the cafe?

WE'RE MOVING FROM CONSUMERS TO CITIZENS

patients are the experts!

Image by: Sandra Howgate