ALAN CHANT

Patient Experience

London Infoday
22 November 2014

What is a Patient?
As seen by a Surgeon:

What is a Patient?
As seen by a Consultant:

What is a Patient?
As seen by a Haematologist:

What is a Patient?
As seen by a Radiologist:
What is a Patient?
As seen by a Research Nurse:

Randomised Controlled Trial (RCT):
Two matched pairs

My Patient Journey
(March 2011 – Dec 2012)

- Diagnosis of multiple myeloma
  - Visit to the GP with back pain (5 weeks) A&E Wexham Park
  - Spinal tumour stabilisation with titanium rods / radiotherapy
  - Partial paralysis and bladder complications
  - Plus life-threatening UTI and left kidney removal
  - Pain in sacrum / radiotherapy - confirmed myeloma

- In-patient in three hospitals
- Out-patient in four others
- Numerous procedures – radiotherapy, chemotherapy, bone marrow and liver biopsies and urological procedures
- Scans - MRIs, CT Scans, Ultrasounds, X-Rays
- Numerous wards – orthopaedics, oncology, haematology, urology & rehabilitation
- Stem cell transplant – Churchill Hospital, Oxford (Sept 2012)

My Patient Journey
(March 2011 – Dec 2012)

- Intensive 18 month period – including 5 months in hospital
- A life-changing illness
- Enduring terrible bone pain
- Having to learn to walk again
- A life-threatening UTI infection
- Enforced early retirement
- Dealing with lack of control and uncertainty
- Lack of focus and direction in life

My Patient Journey
A Light Bulb Moment (LBM)
My Patient Journey

Don’t be a victim - use the patient experience!

My Patient Journey – Motivation

• Positive experience in Thames Valley & Churchill Hospitals
  – Especially during Stem Cell Transplant
  – Informative, supportive, caring, inspired trust, professional and positive culture
  – Motivation to give something back to the NHS, Oxford & Thames Valley Hospitals
• My previous background:
  – 40 years in companies; 22 years at Director level
  – Marketing Director in 4 companies
  – Marketing starts with consumer needs (patient)
  – Consumer research experience (40 years)
• Personal challenge of another culture – NHS / Charities
• To learn more about my own condition

My Patient Experience - Directions

POSITIVE EXPERIENCE

My Patient Experience - Directions

MYELOMA ROUTE

HOSPITAL ROUTE

PATIENT & PUBLIC INVOLVEMENT (PPI) IN RESEARCH ROUTE

My Patient Experience - Directions

– Myeloma UK Support Group (Reading)
– Myeloma UK 5 Clinical Trial (MUK5)
– NICE Myeloma Guideline Development Group
– Member of OUH NHS Trust
– Trustee of OUH Charitable Funds
– Cancer Research UK Early Diagnosis Group
– UK Clinical Research Collaboration Board
– NIHR Programme Grant for Applied Research
– TVCRN Steering Group & Consumer Research Partnership
– Oxford BRC PPI Experiences - Project and Patients Involved In Research (PAIR)
– Member of Macmillan Cancer Voices
– Applicant on 3 grant applications
– NIHR national advertising campaign

My Patient Experience - Directions

MYELOMA ROUTE

HOSPITAL ROUTE

PATIENT & PUBLIC INVOLVEMENT (PPI) IN RESEARCH ROUTE

My Patient Experience - Directions

– Myeloma UK Support Group (Reading)
– Myeloma UK 5 Clinical Trial (MUK5)
– NICE Myeloma Guideline Development Group
– Member of OUH NHS Trust
– Trustee of OUH Charitable Funds
– Cancer Research UK Early Diagnosis Group
– UK Clinical Research Collaboration Board
– NIHR Programme Grant for Applied Research
– TVCRN Steering Group & Consumer Research Partnership
– Oxford BRC PPI Experiences - Project and Patients Involved In Research (PAIR)
– Member of Macmillan Cancer Voices
– Applicant on 3 grant applications
– NIHR national advertising campaign

My Patient Journey – MUK5 Trial
My Patient Journey – MUK5 Trial

- Trial (July 2013) – Carfilzomib vs Velcade
  - Randomised (66%) to Carfilzomib, Cyclophosphamide & Dexamethasone (CCD)
  - 6 months of infusions
  - 6 days in a four week cycle
- Maintenance 1 (Feb 2014)
  - Randomised (50%) to Carfilzomib
  - 6 months
  - 4 days in a four week cycle
- Maintenance 2 (July 2014)
  - 12 months Carfilzomib
  - 2 days in a four week cycle

My Patient Journey – MUK5 Trial

- Benefits:
  - Continuous monitoring
  - Registrar review every 4 weeks
  - Consultant review every 2-3 months
  - Access to new drug sooner
  - Helping to provide the drugs for future patients
  - Zero paraproteins after 3 months (Oct 2013)
  - Remission declared after 6 months (Feb 2014)
- Downsides:
  - Frequent travelling to Churchill Hospital
  - Tablets
  - Needles!

My Patient Journey – MUK5 Trial

- Frustration:
  - Time for trial = 2 years long
  - Time for recruiting target 300 patients = 6 years
  - Time for approval = 72 years
  - Total time = 10 years

Complex / confusing structure of NHS organisations & charities – where to start, how to break in, especially whilst in Transition mode
- Jargon / medical terms – e.g. proteasome inhibitor, nephrectomy
- Acronyms – e.g. TVCRN, NIHR CRN CC
- Research terms – e.g. randomised double blind matched pair
- An alien culture – no previous experience
- Daunting - Highly educated people (BA, MSc, PhD & Professors) - Hierarchy and deference – patients on the lower rung?
- No PPI template – no guide to qualifications & abilities required

My PPI Journey - Barriers

My PPI Journey – Benefits

- Patient perspective – improving patient outcomes
- Patient language – plain English, lay terms
- Independent voice / challenging – e.g. asking the dumb questions, constructive challenging
- Action oriented / benefit driven – delivering results
- Business experience & skills - e.g. decision making
- Research literacy – understanding clinical techniques
- Document reading / writing ability – e.g. Word usage
- Complementary experience – the many aspects of PPI

My Myeloma Journey to Date – Downside

- Mobility restrictions
- Urology problems
- Sleeplessness
- Tiredness at times
- Side effects of drugs (e.g. Dexamethasone)
- Dental issue - ONJ
- Confidence issue in taking holidays abroad
- Enforced early retirement
- Uncertainty – relapse / remission cycle

11/24/2014
My Myeloma Journey to Date – Upside

- Quality of care in hospitals has been exceptional
- MUKS Trial provided access to a drug sooner
- PPI provided a worthwhile life-focus again
- PPI rekindled my skills – meetings, collaborating, proposal writing, presenting etc.
- Both helped regain control and dealing with uncertainty
- Regained my confidence
- Provided a learning opportunity – PPI training, clinical research knowledge, NHS

My Myeloma Journey - Wish List

- Earlier diagnosis of Myeloma
  - UK has the worst cancer survival rate in Europe
  - Myeloma has highest rate of delay in diagnosis of all cancers:
    - 51% patients take 3 or more visits to GP
    - 38% diagnosed at A&E (vs 23% for all cancers)
- New drugs sooner
  - MABs, genome sequencing, personalised medicine
  - RCTs vs Adaptive Licensing
  - Faster MHRA / NICE approvals / EMA / International approvals
  - Praise for Myeloma UK Clinical Trials Network

My Myeloma Journey - Wish List

- Equality of treatment throughout UK
  - Standardised treatment pathways
  - Example: Bisphosphonates Zometa vs Pamidronate
  - NICE Guidelines will help (2015)
- PPI in Myeloma UK?
  - A rare cancer charity punching above its weight
  - Harness the patient knowledge and commitment
  - In-house or outside committees/groups needing a Myeloma voice
  - Review strategic or operational papers

A Patient Thank You.....

- To the staff of the NHS hospitals – for their exceptional care and treatment
- To the Haematology consultants – for expert diagnosis and treatment
- To the Clinical Nurse Specialists – for dedicated cancer care
- To the specialists – surgeons, physiotherapists, radiotherapists etc
- To the research nurses – for managing clinical trials
- To Myeloma UK & Support Groups – for being there for us

and finally......to my wife

Thank you.....

Questions?