



HOW DO WE DEMONSTRATE  
THE BENEFITS OF INVOLVING  
THE PUBLIC IN RESEARCH?



14TH JANUARY 2015, AINTREE RACECOURSE

# HOW CAN WE DEMONSTRATE THE BENEFITS OF INVOLVING THE PUBLIC IN RESEARCH?

WELCOME!

ENJOY YOUR SURROUNDINGS, AND REMEMBER...

YOU SET THE AGENDA!

INTRODUCING OUR FIRST SPEAKER...

**STUART EGLIN**

HELLO!

MY ROLE IS TO BE PROVOCATIVE...

FOCUS ON EVIDENCE

WE'VE GOT COMMON GOALS...

**SIMON DENEGRİ**

WHAT WILL BE PERSUASIVE TO THEM?

**THINK ABOUT THE AUDIENCE FIRST**

**ACCESSIBLE AND INTELLIGIBLE WORK**

ONE OF THE PROBLEMS IS A LACK OF EVIDENCE...

I DISAGREE!

THERE IS THE EVIDENCE, BUT HOW DO WE COMMUNICATE & REPRESENT IT?

PICTURES

NUMBERS

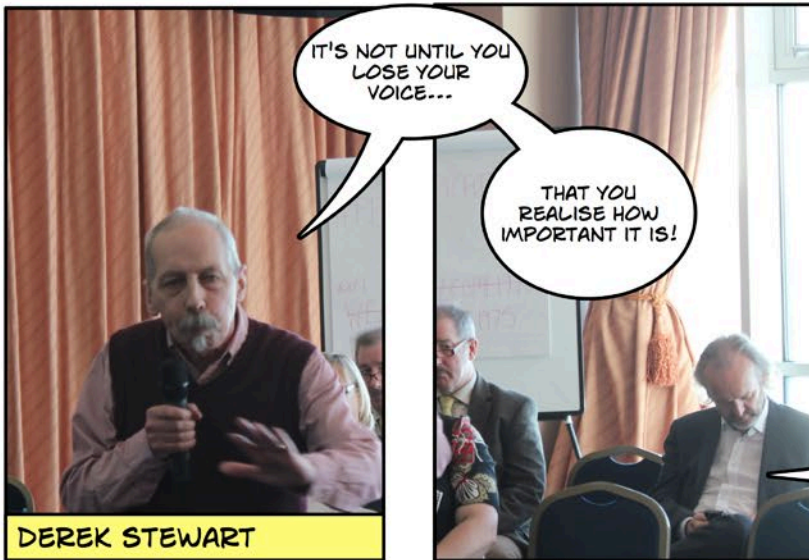
WORDS

DIFFERENT AUDIENCES NEED DIFFERENT WAYS OF SHARING EVIDENCE.

**QUALITY...**

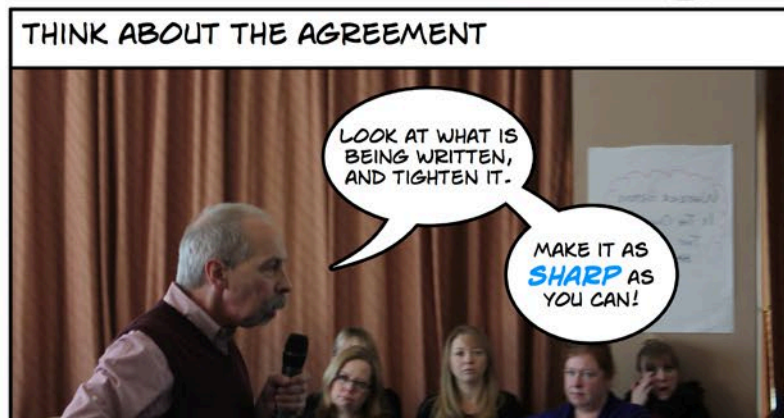
OF KNOWLEDGE...

AND OF PEOPLE'S LIVES!



USING RESEARCH FOR WHAT IT IS INTENDED!

HAVE YOU MADE SOME KIND OF DIFFERENCE TO RESEARCH SO FAR?



INVOLVING CHILDREN IN PAEDIATRIC TRIALS

SHOULD RESEARCH BE PART OF THE CURRICULUM?

DIFFERENT MODELS...

DIFFERENT APPROACH...

AND DIFFERENT MATERIALS!

WE SHOULD APPROACH CHILDREN WHO AREN'T SERVICE USERS....

WHAT ARE THE BARRIERS?

PATERNALISM

INCONSISTENCIES IN RESEARCH ETHICS

PATIENT AMBASSADORS- PROS AND CONS

SHOULD WE CALL THEM CHAMPIONS?

LET'S TAKE THE ROLE OUT INTO THE COMMUNITY!

OR OUTREACH WORKERS?

WE SHOULD EXTEND THE MASSIVE NHS VOLUNTEER BASE INTO RESEARCH ROLES!

IS IT ACCEPTABLE IN A CLINICAL SETTING?

CAPTURING PATIENT IDEAS FOR RESEARCH IN REAL TIME

WHAT IS REAL TIME DATA?

WE NEED TO ENCOURAGE THE NHS TO USE DATA COLLECTED BY PATIENTS EVERY DAY!

HOW DO WE COLLECT REAL TIME DATA?

CREATING MORE RESEARCH ACTIVE COMMUNITIES...

ENGAGE WITH SELDOM HEARD GROUPS...

WHY CAN'T THE DISEASE MODEL OF MENTAL DISTRESS BE REPLACED BY A SOCIAL MODEL?

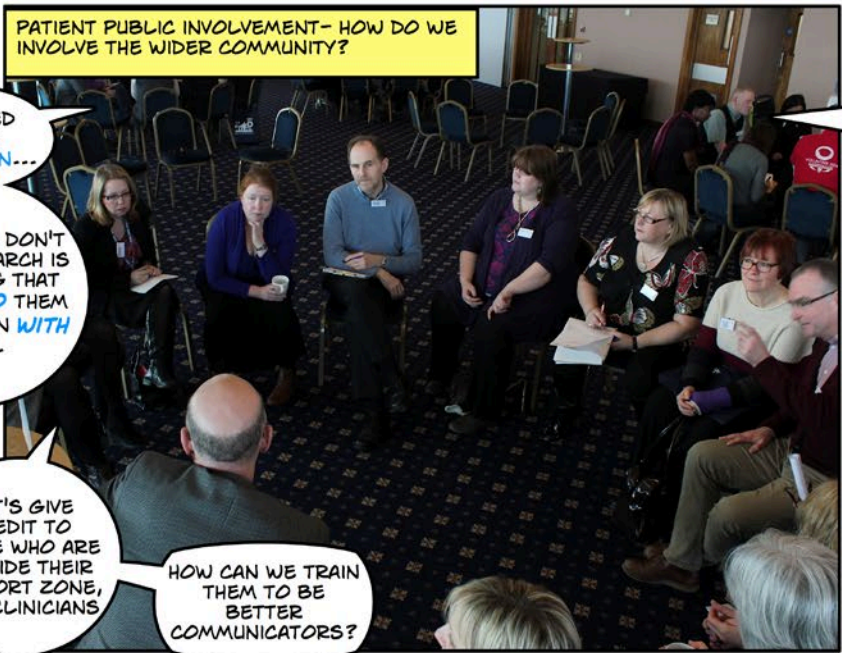


THE PROBLEM IS THAT PSYCHIATRISTS THINK THAT THEY'RE REAL DOCTORS!  
AND THE DUBIOUS ROLE OF PHARMECECUTICAL INDUSTRIES...

PEOPLE ARE AGITATED AND DISCONTENT...  
BUT THIS IS A POLITICAL PROBLEM!  
SUFFERING IS NOT AN ILLNESS!

THERE IS A CRISIS!

PATIENT PUBLIC INVOLVEMENT- HOW DO WE INVOLVE THE WIDER COMMUNITY?



WE NEED MORE EDUCATION...

SO PEOPLE DON'T THINK RESEARCH IS SOMETHING THAT HAPPENS TO THEM RATHER THAN WITH THEM.

LET'S GIVE CREDIT TO THOSE WHO ARE OUTSIDE THEIR COMFORT ZONE, LIKE CLINICIANS

HOW CAN WE TRAIN THEM TO BE BETTER COMMUNICATORS?

LET'S GET PEOPLE INVOLVED FROM THE VERY BEGINNING!

...BEFORE THE GRANT APPLICATION GETS WRITTEN.

HOW DO WE PROPERLY RESOURCE PUBLIC ENGAGEMENT, NOT JUST ON A PROJECT BY PROJECT BASIS?



CREATIVE USE OF SOCIAL MEDIA

DOING THINGS DIFFERENTLY WITH FUNDING

WE NEED TO MAKE PPI A DEDICATED PART OF RESEARCH FUNDING

MAKE IT A CHARGABLE OVERHEAD!

HOW CAN PATIENTS PROPERLY DRIVE RESEARCH?

IT'S ALL ABOUT **LEADERSHIP**

PATIENTS SHOULD BE ABLE TO LOBBY FOR WHAT RESEARCH THEY WANT DONE...

FOR EXAMPLE, THE ARTHRITIS SOCIETY KNOW WHAT NEEDS TO BE DONE...

BUT THE PEOPLE WHO FUND THE RESEARCH HAVE A DIFFERENT OPINION!

**ASK** PATIENTS WHAT HAS WORKED...

THEY'RE THE **EXPERTS!**

HOW CAN WE USE EVIDENCE TO CONTINUALLY IMPROVE PPI?

WE NEED TO ASK THE RIGHT QUESTIONS...

WHY?

WHO FOR?

WE NEED TO PLAN FROM THE BEGINNING WHAT YOU CAN ACHIEVE

WHAT DOES SUCCESS LOOK LIKE?

DIFFERENT EVIDENCE...

FOR DIFFERENT AUDIENCES.

HOW CAN WE SUPPORT THE PUBLIC WHEN THEY'RE INVOLVED IN RESEARCH?

THE FUNDING STREAMS JUST AREN'T THERE...

SO WE NEED INCENTIVES THAT AREN'T JUST ABOUT MONEY.

BE CLEAR ABOUT WHAT'S EXPECTED OF PARTICIPANTS

TOKEN GIFTS...

TRAINING AND TEACHING NEW SKILLS..

TAKE THE MEETING TO THEM

WE NEED TO ASK...

WHAT IS IT THAT YOU **EXPECT** AND **NEED** FROM THIS PROCESS?



WHAT ARE THE BEST WAYS TO ENGAGE THE PUBLIC?

THERE'S LIMITED INCENTIVE IN THE UK...

NOT LIKE IN THE US WHERE PEOPLE HAVE TO PAY FOR HEALTHCARE!

WE NEED TO SELL THE BENEFITS OF RESEARCH...

SHOW HOW IT HELPS

TAKING THE MESSAGE TO THE PUBLIC...

USE THE FREE PRESS!

IT'S ALL ABOUT **DISSEMINATION**



WHY DO WE HAVE TO JUSTIFY PPI?

WE DON'T EVALUATE CLINICIANS, SO WHY DO WE HAVE TO EVALUATE PPI?

MORAL STATUS...

MEASURE IMPACT...

IT'S ALL ABOUT POWER AND RELATIONSHIPS

**CHANGING CULTURES!**



QUALITY & DIVERSITY

HOW DO WE DO THIS?

IMPROVE WELLBEING AND SELF ESTEEM...

THE RIGHT MENTAL ATTITUDE CAN KEEP SOME PEOPLE OUT OF HOSPITAL!

THERE'S LOTS OF PRESSURE ON THE NHS IN PRIMARY & ACUTE CARE...

CAN WE KEEP PEOPLE FROM UNNECESSARILY USING A&E AND HOSPITAL BEDS TO FREE UP MORE REVENUE FOR PPI?

USING ALT-METRICS TO DEMONSTRATE THE EFFECTIVENESS OF PPI

ERM, WHAT ARE ALT-METRICS?

THEY'RE THE RECORDS OF WHO'S ACCESSED WHAT ONLINE.

POTENTIAL OF USING SOCIAL MEDIA EFFECTIVELY

HOW IS KNOWLEDGE TRANSFERRED?

WE NEED TO TRACK THE METRICS- HOW IS THIS INFORMATION BEING USED?

WHEN SHOULD WE HAVE PPI FOR THE BEST IMPACT?

WE NEED PPI THROUGHOUT THE WHOLE PROCESS...

WITH EVALUATION AT EACH STEP!

FROM DRIVING THE RESEARCH QUESTION..

THROUGH TO DISSEMINATION

SHOULD RESEARCH BE FUNDED IF IT DOESN'T INCLUDE PPI?

YES.

IF THERE'S GOOD RESEARCH & JUSTIFICATION FOR WHY NOT!



