Making the difference: How CCQI patients and carers can influence change in mental health services

Chair’s Welcome: Angela Etherington.
Real life stories: the impact of patients and carer involvement on mental health services: Professor Mike Crawford
Patient and carer involvement is critical to the CCQI.

Thanks to your input, the following has been possible....
Because of you, standards have been added and amended, to help make sure we’re measuring services against the things that are important to you.
E.g, patient and carer feedback directly led to this standard: “Young people waiting for assessment and treatment can access help while they wait for an appointment”.
“Young people (on inpatient units) have access to the internet for recreational purpose.” Clinicians felt this standard would be too risky... but CCQI young patient reps persuaded them otherwise.
Thanks to your ideas, we’re able to adapt CCQI questionnaires and methods to get better response rates.
You often bring an independent view to CCQI work and can ask challenging questions and dig a little deeper, whether on a review or analysing data.
Thanks to you interviewing patients and carers for the CCQI, we can be more confident that people are speaking freely, helping to make the data more valid.
Thanks to your attitude and fresh perspective, you often bring a practical, pragmatic, ‘can-do’ approach to problems.
By joining focus groups, you help us make sense of our audit and research data from a patient and carer perspective. Your voice shapes the recommendations we write for services to meet.
Thanks to your input in meetings and on reviews, services have made many direct changes to things like ward rules, food, environment and activities.
Thanks to the awareness training provided by patients and carers, CCQI staff now understand more about living with things like psychosis, self-harm and eating disorders.
By giving presentations at our CCQI events, you are helping to change practice. Patient and carer sessions are consistently rated as “highly powerful and influential”.
By planning and attending days like today, to help improve our work.
Because of your experience of different services, initiatives, projects and campaigns, you help us keep up to date with what’s happening out there.
Thanks to the other skills and experiences you bring to the role, you teach us new things all the time; not just about patient and carer involvement. Things like planning events, teaching skills, design skills, research skills, marketing skills and...life experience.
CCQI Staff member: “Service users and carers tell it like it is. They know what it’s like to be on a ward, to sleep in the bed, to eat the food, to receive the care (or not)...they can say what the staff are like, how it makes such a difference to be treated well. I've seen staff moved to tears when patients and carers speak from the heart. Attitudes change, then practice changes.”
In summary..

We could not do what we do without you. You add a unique perspective, skills, ideas, a pragmatic approach and most of all you add meaning to our work. Thank you!
The impact of working with the CCQI from a personal perspective.
- John Copping and Satveer Nijjar
I am John C

Where C is for Carer

OK, that is fine by me

But can I be a carer representative?

Can I perhaps be a representative carer?
“IF I WERE NOT A CARER, I COULD BE HAVING A BALL”

Carers provide – free, and out of love and duty alone - the ‘informal’ part of the service.

They have no significant power, but there is considerable moral strength in their position.

The challenge to the service, and to others like CCQI, is to **respect that position** and gain benefit from it.
We will today be discussing:

A- Influencing change on equal terms
   B - Finding meaning
   C - Participation by looking after yourself
   D - Challenging stigma and discrimination

A is my area – I have been a manager of change

But first, impact of carer involvement on:
   a) MH services and b) working with CCQI
WE ARE ‘INVOLVED’ TO SUPPORT ONE OR MANY ‘SERVICE USERS’

“It is not a crime or a character weakness to have a mental health condition - it is, after all, just an illness - some people with such conditions have sublime gifts”
Service users are clients of the service – most carers are not

Most carers are providers of services – many SUs are not

Carers can offer valuable inputs as:

1 - Co-providers of support for the service's client

2 – Clients of those providing services to carers

3 – Colleagues in the drive towards 'QIPP'

4 – 'Critical friends' for commissioners

5 – Contributors to workforce development

6 – Capable collaborators with CCQI etc.

But, carers must not speak for service users!
I have a very positive reaction to AIMS reviews:

most peer review team are ..........

the host team are usually ..........

the atmosphere is usually ..........

If three standards only (Family & Friends), I would assess:

1 - ............

2 - ............

3 - ............

I assess ...% as excellent, ...% good, ...% fair and ...% weak
I have a very positive reaction to AIMS reviews: most peer review teams are - a joy to work with hosts team are usually – apprehensive but appreciative the atmosphere is usually – positive and friendly

If three standards only (Family & Friends), I would assess:

1 – the morale of the team on the ward
2 – the leadership of the ward manager
3 – the support from the senior managers etc.

I assess - 15% as excellent, 70% good, 10% fair and 5% weak
So what would I like to see as a manager of change?

1 - ..............
2 - ..............
3 - ..............
4 - ..............
5 - ..............
6 - ..............
So what would I like to see as a manager of change?

1 – weak wards twinned with excellent ones
2 – coordinated 'library' of ward/carer information
3 – CCQI to invite Triangle of Care into partnership
4 – standards used as a day-by-day management tool
5 – CQC to extend peer review as alternative to 'inspection'
6 – use of some CCQI reviewers as mentors to the sector
WITH GOOD TEAM-WORK, WE MAY REMOVE A LOG-JAM OR TWO!

THANK YOU

Contact:  copping.jl@gmail.com   01926 403966
Small group discussion: What impact has CCQI work had on you?
Afternoon workshops

1. Influencing change on equal terms – now and in the future - this room.
2. Finding Meaning - Room 1.1 (next to cloakroom).
3. How to participate fully and look after yourself on a peer review day - Room 1.2
4. How patients and carers can help challenge and deal with stigma and discrimination in mental health - Room 1.4.
The Debate: Patients and carers always know best
Final reflections?
Thanks for your input today!

How wonderful it is that nobody need wait a single moment before starting to improve the world.

Anne Frank