

Decision making in head and neck cancer: an ethnographic study of the multidisciplinary team

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Welcome to the century of the patient

To mark the signing of the Salzburg statement on shared decision making, the *BMJ* brought together 14 doctors, patients, academics, and policy makers to discuss how to involve patients in decisions about their health.

Anne Gulland reports

Consent: patients and doctors making decisions together



NHS

“No decision about me, without me”

What do you think about our ideas for making shared decision making happen?

Please tell us what you think by 31 August 2012



'Liberating the NHS: No decision about me without me. A further consultation on proposals to secure shared decision making'

Please see the longer version for more details.

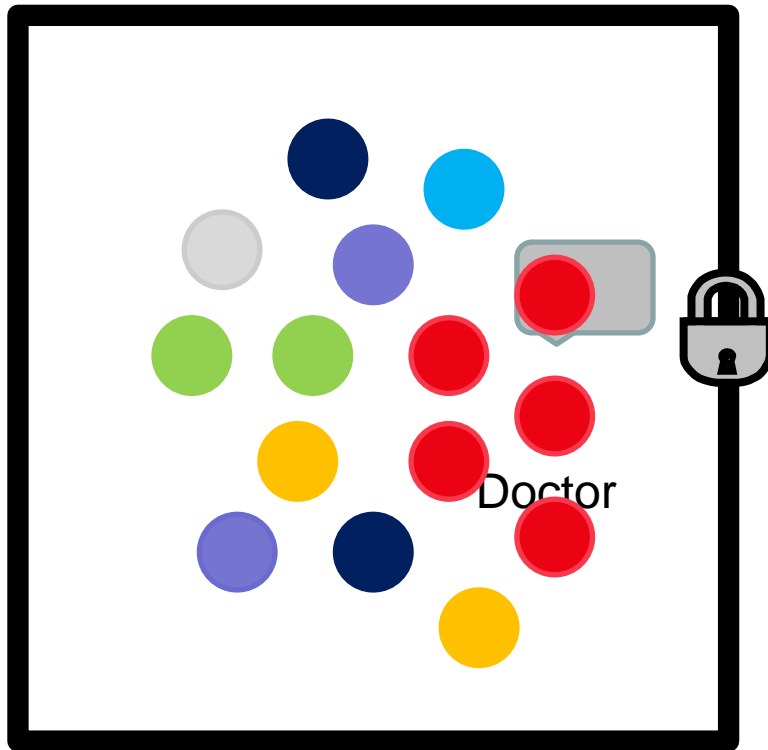
DH Department of Health

Head and neck cancer



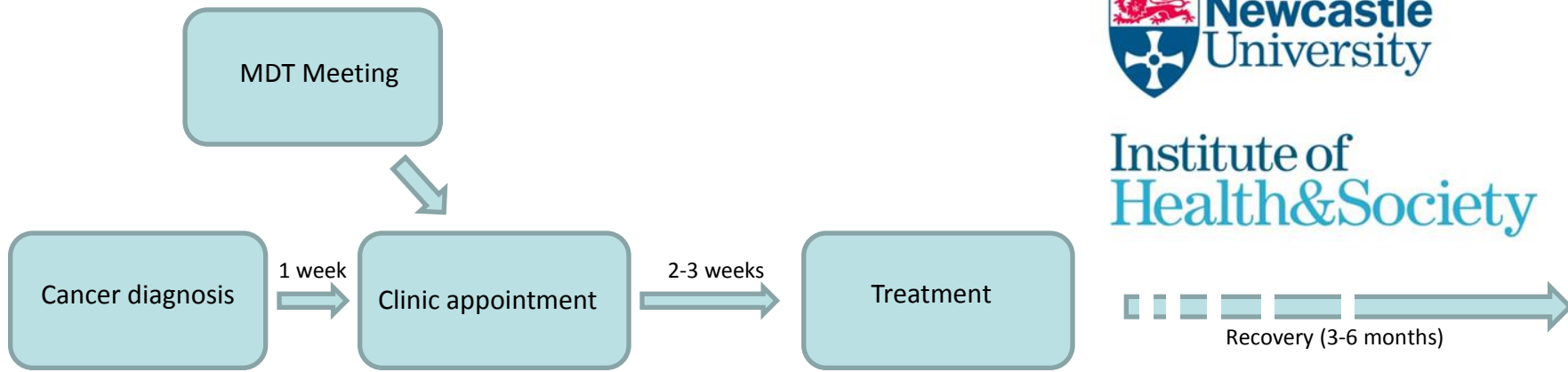





Multi-**D**isciplinary **T**eam

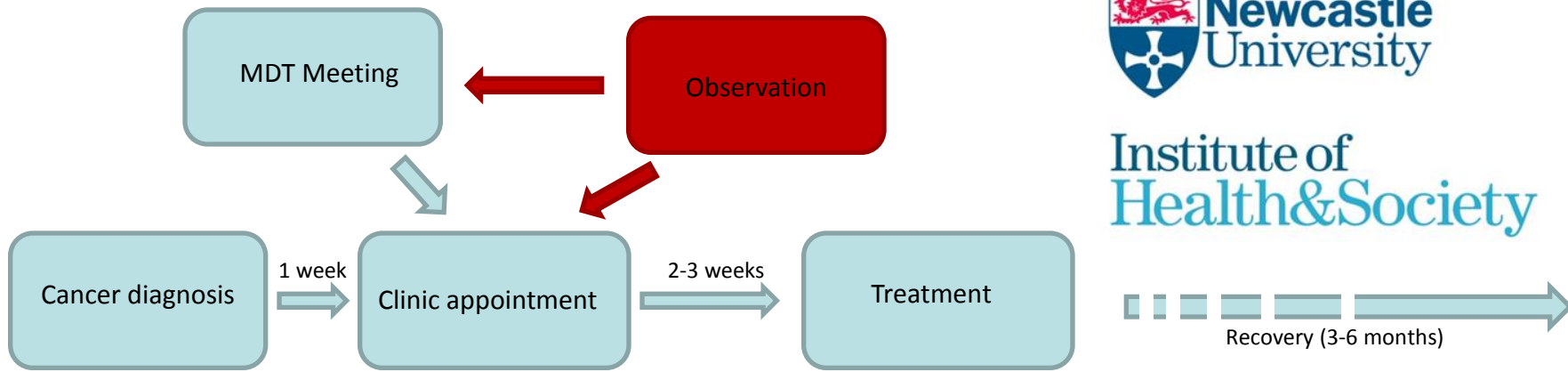





Aim

To examine critically how the MDT manage situations of treatment choice and involve patients



-  Clinical pathway
-  Patient research pathway
-  Staff research pathway



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-  Patient research pathway
-  Staff research pathway



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Data

Observation, MDT meeting for Samuel Black

Max facs surgeon: So shall we see him together

(Silence 10 s)

ENT Surgeon: Depends how you put it to the patient isn't it, you know!

Plastic surgeon: It's one of these things, we've done this before, and you see the patient, and you have two people there, and you confuse the patient even more. I think....

Nurse: It's horrendous, I think it is the worst thing you can do for a patient

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Nurse: Patients just don't know, they just don't know what to do

Max Facs Surgeon: But are we not supposed to give the patient choice?

Results



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- Members of the team often have a clear view of what they think is 'best'

“In general head and neck there often isn’t an option; you’ve got the best treatment that there’s an evidence base for that... once you’ve decided on that option it’s not that I’m deciding on it as a non-surgical oncologist or a surgical oncologist deciding on it; that is the truth as far as we know it...that is at present universally thought to be the best treatment for the patient”

Dr Orange, Oncologist, Interview

Framing



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- If one best treatment is decided by the team, this one treatment option may be delivered to the patient
- If there is a choice, it is often 'framed' to ensure the 'correct' decision is made

“...your skin on the outside will start getting red like it’s had a sun burn-type reaction and on the inside it starts getting red and inflamed as well. And that means that you’ll start having problems like a sore throat and some problems with your swallowing... So, you’ll be put on special mouth washes and you’ll need to be on pain killers and things to help you with that. You’ll feel more poorly if you’re not keeping your strength up so we would arrange [a gastrostomy] before you started the treatment....It’s just a little tube that’s put in your tummy”

Dr Green, Oncologist, Observation, Clinic Appointment

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“The outside of your skin and the inside of your throat will all become quite red and hot and sore and that’s why swallowing will become very, very difficult – probably impossible. Even swallowing your own saliva will be impossible by the time you get to the end of that six weeks.....Even the strongest guys struggle, believe me and by the time they get to six weeks, life is very difficult... because what happens is, you lose the lining of your throat. All the protection that we have from bugs disappears, so infection gets into your throat no problem and you’re overwhelmed....and that’s what usually happens with guys like you who just haven’t got that reserve.”

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Why is this a problem?

- Many treatment decisions are based on values, attitude to risk and opinion: there is sometimes no 'best'
- Uncertainty and difference of opinion is seen as a something which should remain backstage
- Presenting choice is often seen as displaying uncertainty

“I really do not believe it’s fair to say to the patient, “We’re quite uncertain, we don’t know what to do, these are the options, what do you want?” I mean that is just shit because you’re the bloody expert, that’s what they’re paying you for, they can’t walk away thinking, “Christ, even the experts don’t know what to do.” That’s desperately wrong.”

Mr Halifax, Maxillofacial Surgeon, Interview

The consequences

- A lot of the work of decision making takes place in the backstage
- The team attempt to include the patient by building an 'evidential patient' via information
- There is no consensus about how this information should be incorporated into the decision

“You’re just making decisions based on scans and guidelines as opposed to an individual and having somebody ever having had the opportunity to explore not just their physical and psychological status, but their feelings about treatment.... it would be nice to have much more of a feel and a knowledge of the patient before it gets to that MDT”

Interview, Sally, Speech and Language Therapist

Backstage work

- This impacts on any assessment of ‘best interests’
- It means the team can struggle to know how involved the patient would like to be
- This creates a difficulty in the role of the team and their relationship to the patient

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Discussion

- MDT working is the standard of care internationally: all cancer decisions in the UK are made in this setting
- Patient involvement is essential: many treatment decisions are value judgements
- The structure of MDT decision making makes effective patient involvement very difficult

Discussion

- If the patient is to be truly involved, the uncertainty, risk and prognosis associated with the decision must be communicated
- Constructing an 'evidential patient' is almost doomed to failure
- Thus, the MDT should be structured to allow to the patient to be represented via interaction

Acknowledgements



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