

## NICE and Patient Involvement ....What's the point?

### Introduction

The NICE [Consultation on improving how patients and the public can help develop NICE guidance and standards](#) is currently open and was discussed at the Cancer52<sup>i</sup> All Member Meeting on 24th January 2017. As a result of that presentation and follow up Q and As a small working group of Cancer52 members was formed to answer the broad question - 'What's the point?', with the aim of identifying where patient involvement makes (a/any?) difference to NICE process or results and how we could (jointly with NICE?) better manage the time and energy involved from patient groups and patients against what the likely impact is likely to be.

### This is how our members perceive the way NICE considers Patients and Patient Groups views

- Outsiders
- Ignored
- Undervalued
- Disrespected
- Box ticking at best
- Involvement
- Tick-Box
- Inefficient
- Inflexible
- Tick-box
- Superficial
- Side-show

### and this is how our members would optimally want NICE to consider Patients and Patient Groups views during the STA process

- Respected
- Valued
- Influential
- Partners
- Real recognition of patient needs
- Impactful
- Equal Partners
- Voting Rights
- Throughout
- Tailored
- Central
- Genuine
- Impactful

## so what steps do we want that will help bridge the gap between where we are now and where we want to get to?

### 1. clarity, impact and feedback

- **clarity** is required for patient groups so they can understand their impact on an appraisal. Currently, there is no way of telling whether our views have been taken into account or not, or if we've successfully had any influence on a final appraisal decision.
- clarity on where patient groups **can most add value in an appraisal** – where are the areas of uncertainty, where are the gaps in the evidence base? If there was more transparency about this, patient groups could focus on the key areas of an appraisal rather than spending significant time on making points that the committee already agreed with.
- a process that allows the patient voice to actually have a **measurable impact**. Ideally this would be a vote - as it is noticeable that patients are the only ones who aren't allowed one.
- If there's no vote ... then alternatively/additionally make patient views part of a **comprehensive scoring process** (of which the QALY is only one part)
- a **feedback** process that demonstrates that the voice of the patient has been heard, on a point by point basis, and responded to in a constructive and meaningful way. The response doesn't of course need to an agreement with every point raised, but one that shows it's been considered. NICE used to do this for comments made during the scoping process. However, comments were usually 'Comments noted. No action required'

## 2. flexibility and culture

- a **flexibility in process** that allows the patient and other stakeholder input at the committee meeting stage to be placed early on the agenda and not necessitate patient presence throughout the initial health economics presentation
- a **flexibility in technology** that allows patients not to have to travel - from hospital? to the meeting. Teleconference, webinar, etc
- a **shift in tone** from one that appears to refer to everyone, apart from the person who has a rare or less common cancer, as 'professional'
- **shift in culture** at NICE which means that from the top down the patient voice is recognised as a key driver in decision making, not one that comes in late in the day and is accommodated but not commented on or measured and coming from the bottom up

## 3. process changes

- **reinstatement of scoping workshops** and patient involvement therein ... as the workshops seem to have disappeared. They are important as they set the tone, scope and context for the whole process and mean that patients do not come into the process early enough
- **early involvement** of patients in the process
- a **conversation on a particular appraisal** between NICE and patient groups pre the scoping workshop that helps identify where all parties think key points for patient involvement in the decision making process on this particular decision will be. Aim of this discussion is to prevent patient group time being wasted and to help focus effort where it will have most impact
- acknowledgement that the **PACE meetings**<sup>ii</sup> held by SMC are regarded by patient groups as best practice, ahead of the curve etc
- NICE is now the only HTA body in the UK that **doesn't hold patient focused meetings like PACE** (a particular issue for rare and less common cancers, as PACE is only held for orphan drugs and End of Life) – could this be a review panel that is held throughout the process?
- There should be greater flexibility on **when patients can be involved**. An example was cited where towards the end of an appraisal, it became apparent that because of the direction of travel, a particular patient case study would be valuable to illustrate a particular point. However, as that patient had not been registered at the beginning of the process, they were not permitted to be involved. As it is not always possible at the outset to know which individual patients could best support an appraisal, greater flexibility should be permitted.
- We need to find a way of **capturing quality of life issues**, the impact of a new drug that really changes the lives of patients and carers. There was a previous attempt to do this through Value Based Pricing – this died a death not **because Quality of Life was deemed unimportant**, but because it was difficult to find a way of capturing it. If quantifying it remains a challenge, we need the HTA process to find a way to include qualitative statements about improvements in QoL brought about by a new drug.

## 4. acknowledgement

- acknowledgement that especially in the case of rare and less common cancers that the patient has a **unique level of knowledge** to bring to the debate
- acknowledgement that at the moment, **many man hours spent by patients and patient groups** over a considerable time period is in no way measured or acknowledged



## Contributors

Cancer52 would like to thank the following members who grouped together specifically in response to the challenge to produce briefing on this topic.

[Bloodwise](#)

[CLL Support Association](#)

[GIST Support UK](#)

[Leukaemia Care](#)

[The Lymphoedema Support Network](#)

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## Further information

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<sup>i</sup> **52 per cent** (recent statistics show an increase to **54%**) of UK cancer deaths are from the less common cancers. Despite this, rare and less common cancers remain severely under represented and under-funded across all areas, including policy, services and research. Cancer52 is an alliance of more than **90** organisations working to address this inequality and improve outcomes for patients with these highly challenging diseases.

<sup>ii</sup> "Speaking up for patients- Patient organisation involvement in Health Technology Assessment, with a focus on Patient and Clinical Engagement at the Scottish Medicines Consortium

<http://www.cancer52.org.uk/wp-content/uploads/2014/09/PACE-SMC-Report-LB-comments-formatted.pdf>