

Background

Public and patient involvement (PPI) in health research is reported to result in enhanced study design, increased recruitment and research questions that are more relevant to patients' needs. For a highly curable cancer such as Wilms Tumour (WT), it is essential to collaborate with families to ensure research is focused on what is important to them.

Aims

1. To involve parents of children who have been treated for WT in the identification of research priorities
2. To establish a network of parents for future collaborative WT research

Methods

Families with experience of WT, identified at clinic visits, were invited to attend a meeting held at Great Ormond Street Hospital, London..

Results

5 parents of WT survivors and 3 bereaved parents attended the lunch-time meeting on Thursday 25 April, 2013. The meeting started with introductions and establishing ground rules and confidentiality. The remit of the group was explained as a forum for learning about current WT research and discussion of research priorities. The importance of parental experience was emphasised to influence the future design of high-quality clinical trials. The results of the SIOP 2001 trial were presented to the group with an opportunity for questions.

Parents were then asked to form pairs for facilitated discussion of research priorities. Broad themes were identified following the small group discussion and presented to the group for ranking.

Two quality improvement themes emerged:

- i. improving early diagnosis for childhood cancer by educating GPs;
- ii. better information and support for parents

Three research themes emerged:

- i. improving overall survival by prioritising treatment for relapsed WT patients and new drug discovery;
- ii. better understanding of predicting risk of relapse on an individual patient basis and,
- iii. reducing toxic and late effects of treatment.

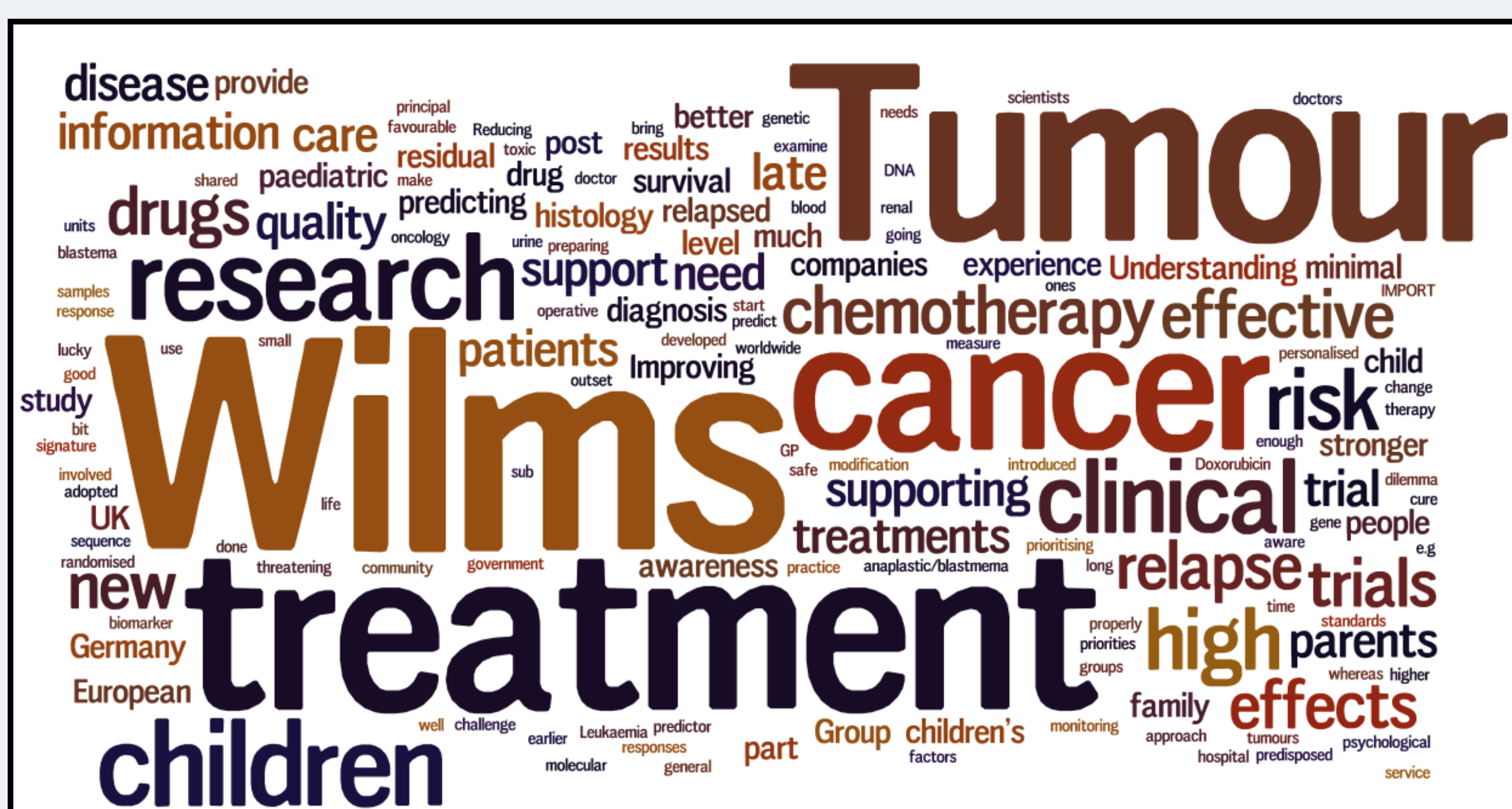


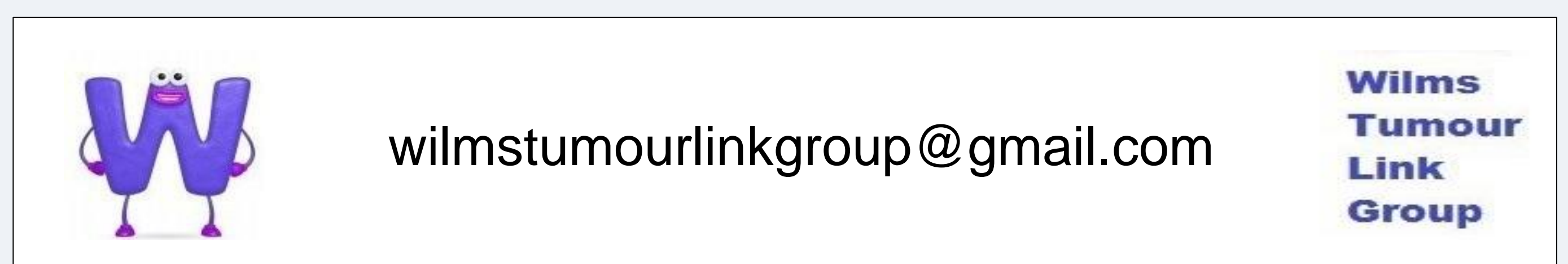
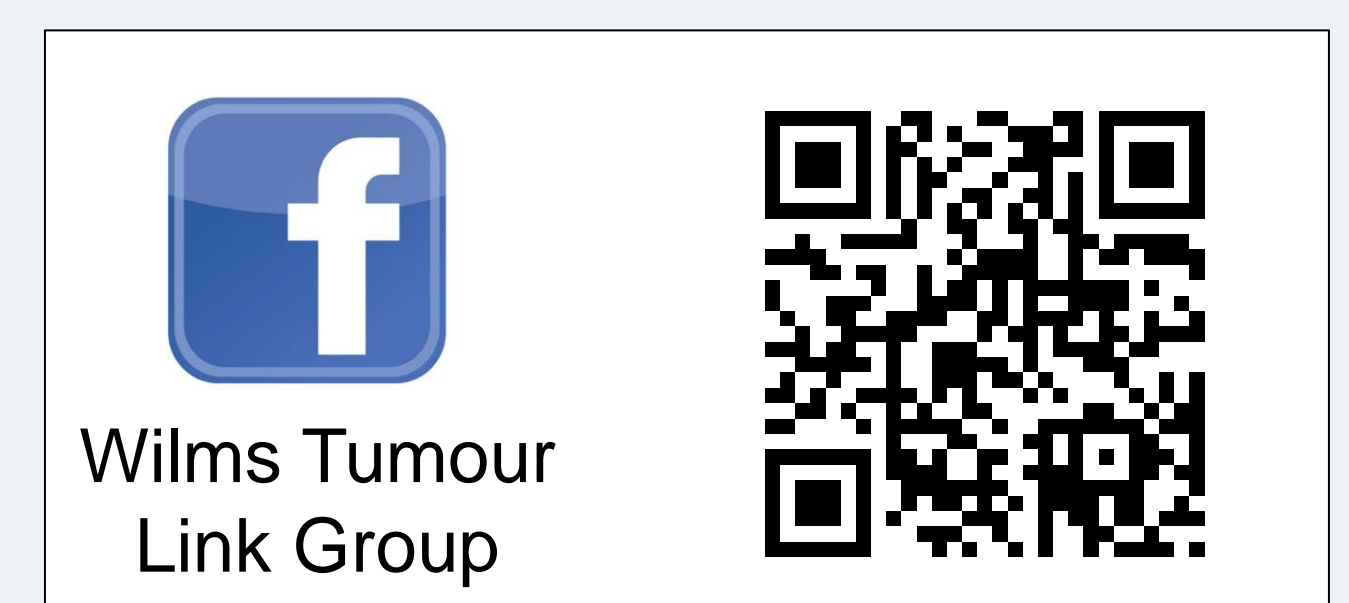
Fig. 1: Weighted list of word frequency during meeting



Fig. 2: Selected quotes from parents during meeting

Future of the group

Parents expressed enthusiasm to expand the group further by establishing a Facebook group and a Twitter account and named themselves "Wilms Tumour Link Group".



Relevance

Most funders now require a plan for PPI in grant applications. Parents of children with cancer can offer "experiential expertise" to identify research priorities. The Wilms Tumour Link Group is an example of how this may be achieved.

Acknowledgements:

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