



NanoMed Round Table Patients' Needs Working Group

Annex 1 – Results from Online Scoping Survey for the Pilot Study

The results of the Patients' Needs Working Group's online scoping survey are provided below.

The survey was available online during June, July and August 2009 and was distributed to patients and patient organisations by the members of the Patients' Needs Working Group. Before publishing the survey, the Working Group sought comments on a draft version from:

- Genetic Interest Group staff members
- The Irish Medical Research Charities Group Board

List of Survey Questions

N.B. where multiple choice answers were offered, these are indicated in parentheses.

- **About You**

1. Are you a: leader of a patient organisation, patient, member of a patient organisation, carer/relative of a patient, doctor/clinician, nurse/counsellor, none of the above? (Please select all that apply)
2. Where do you live? (Please state country)
3. Which disease are you interested in/affected by?

- **About Nanomedicine**

1. Have you heard of any use of nanomedicine within your condition area? (Yes, no, don't know)
2. Do you support the use of nanotechnology in medicine? (1 = not at all; 5 = strongly)
3. Within current spending, would you like to see more nanomedicine research into your condition? (Yes, no, don't know)
4. How safe do you think nanomedicine is? (1 = not safe at all; 5 = very safe)
5. Would you like more information on nanomedicine? (Yes, no, don't know)

Nanomed Round Table

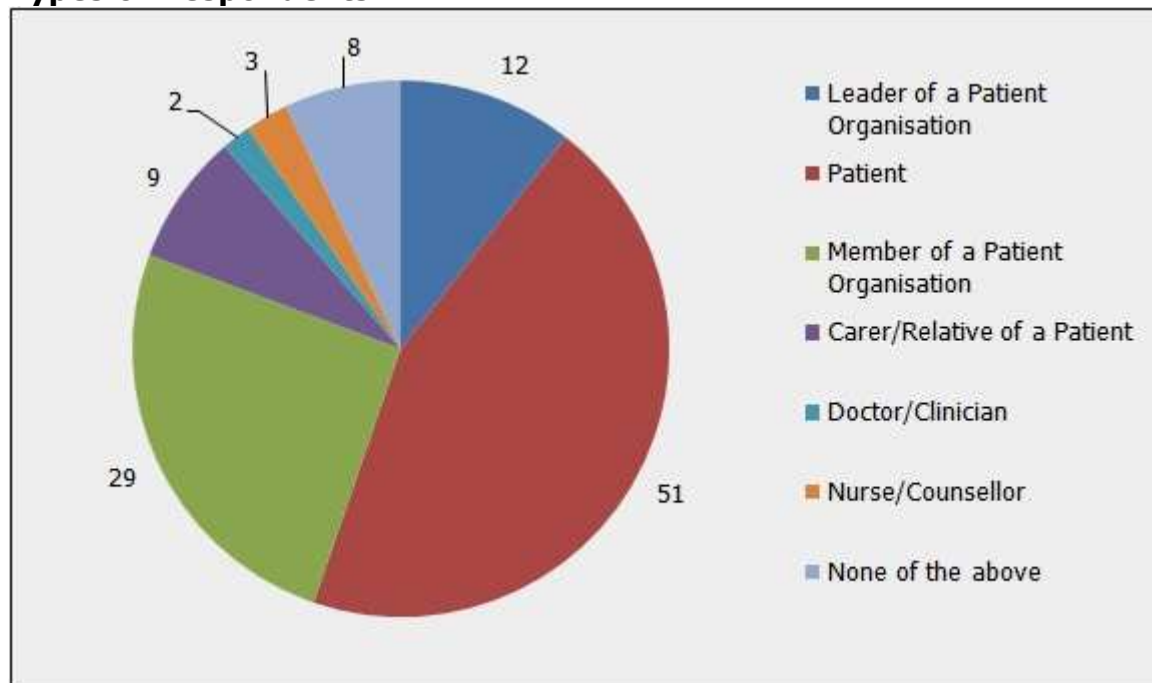
- **More information on Nanomedicine**

1. How would you like to receive this information? (Internet, paper-based, in person/face-to-face, TV)
2. Who would you like to receive this information from? (The media, clinicians, patient organisations, European Institutions e.g. European Commission and European Parliament, your national government)

A text box was also provided for any additional comments.

Nanomed Round Table

Types of Respondents¹



Respondents' Countries of Residence

Country of Residence	Number of Respondents
Belgium	2
Ireland	6
Lithuania	2
Netherlands	2
Romania	1
Slovenia	1
Spain	1
Sweden	1
Switzerland	29
Turkey	1
UK (England, Scotland & Wales)	40
Unspecified	1
Rest of World (Australia, Iran, Israel) ²	5
Total	92

¹ Respondents were able to choose more than one category, so responses total more than 100 per cent.

² Not included in analysis.

Nanomed Round Table

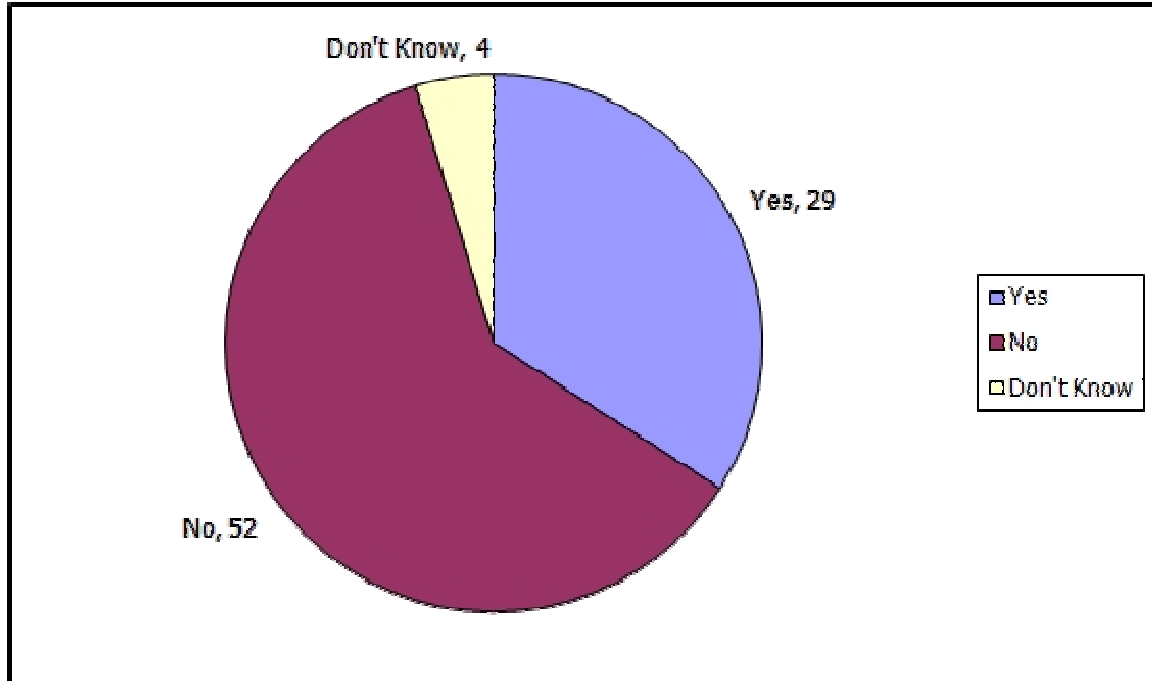
Condition Areas that Respondents were Interested in/Affected by³

Condition Area	Number of Respondents
All genetic conditions	2
Alpha1 Antrypsin Deficiency	3
Autism spectrum disorder	1
Behcets Syndrome	2
Brainstem Cavernoma	2
Cancer	3
COPD	1
Cystic Fibrosis	2
Epilepsy	1
Fragile X Syndrome	1
Glaucoma	1
Gorlin Syndrome	1
Klinefelter's Syndrome	1
MCADD	1
NAIT/FMAIT Neonatal alloimmune thrombocytopenia	1
Neurofibromatosis	1
Neurological	1
Osteoarthritis	1
Osteogenesis Imperfecta	1
Parkinson's Disease	51
Retinal disorders	3
Total mental failure	1
Trisomy 18	1
Wildervanck Syndrome	1
Unspecified	1
None	2
Total	87

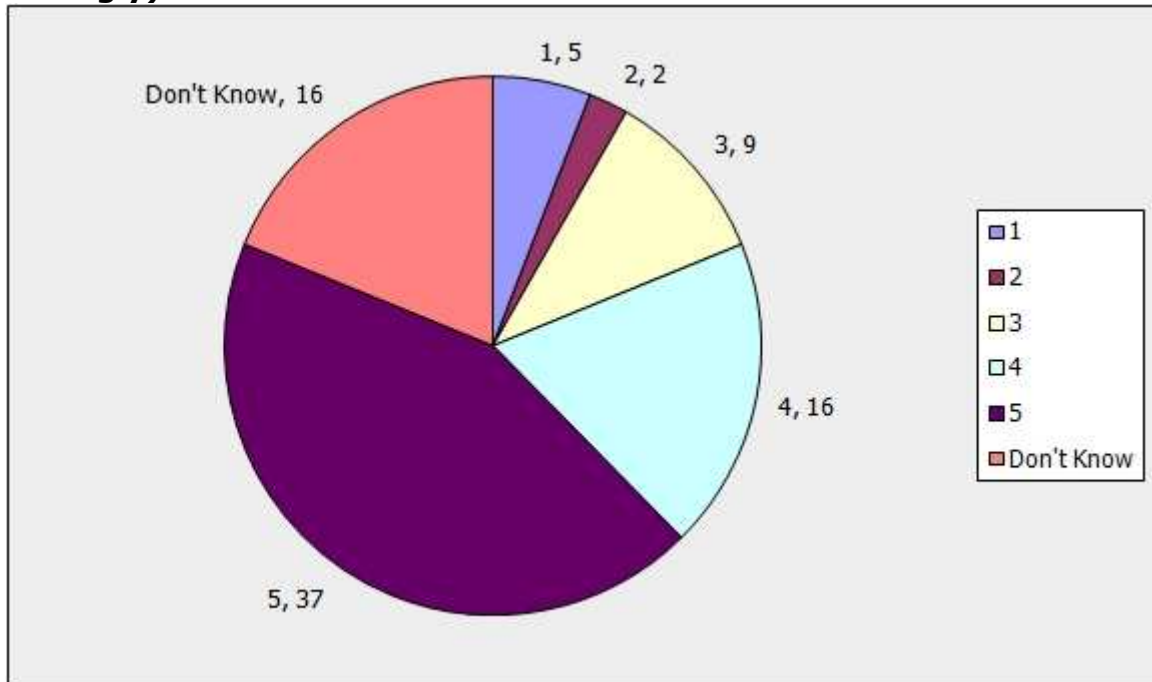
³ Some respondents indicated more than one condition area. It should also be noted that many of the conditions with small numbers of respondents are in fact rare conditions, so the numbers could not realistically be expected to be higher than this.

Nanomed Round Table

Have you heard of any use of nanomedicine within your condition area?

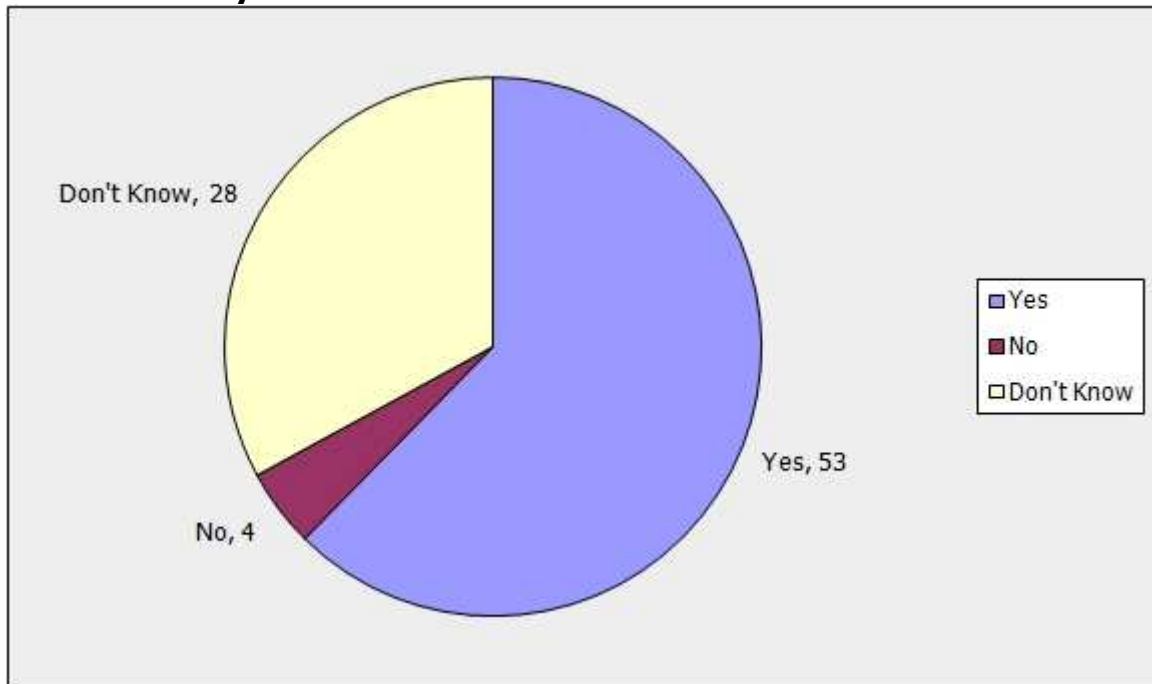


Do you support the use of nanotechnology in medicine? (1 = Not at all; 5 = Strongly)

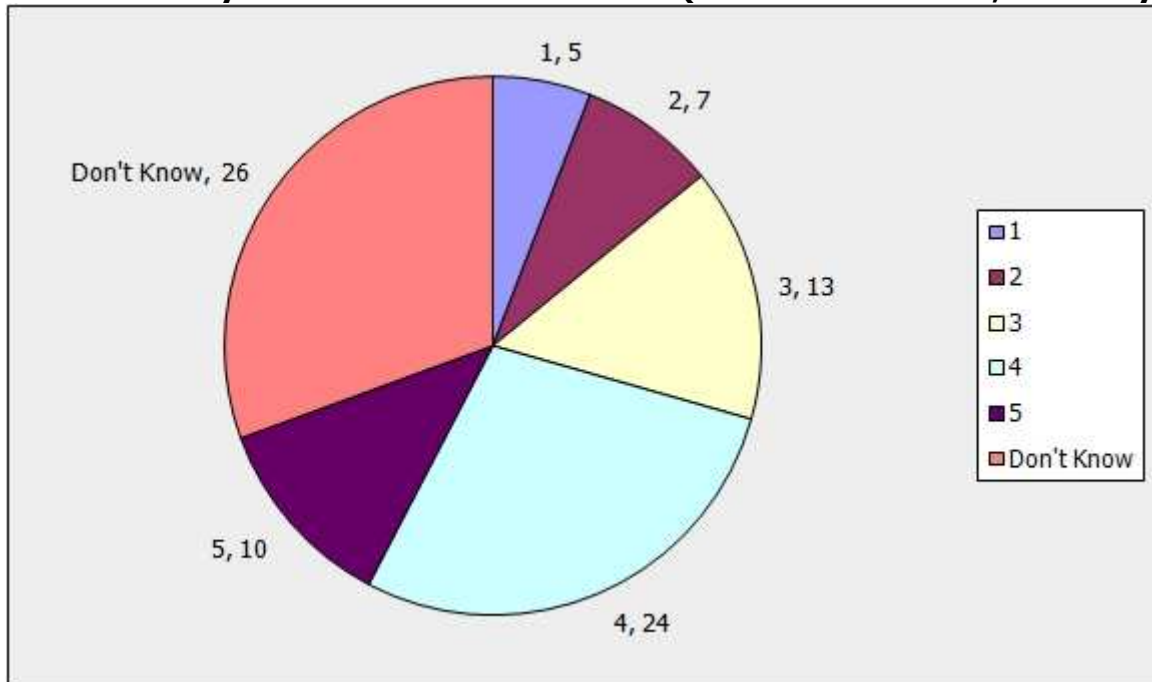


Nanomed Round Table

Within current spending, would you like to see more nanomedicine research into your condition?

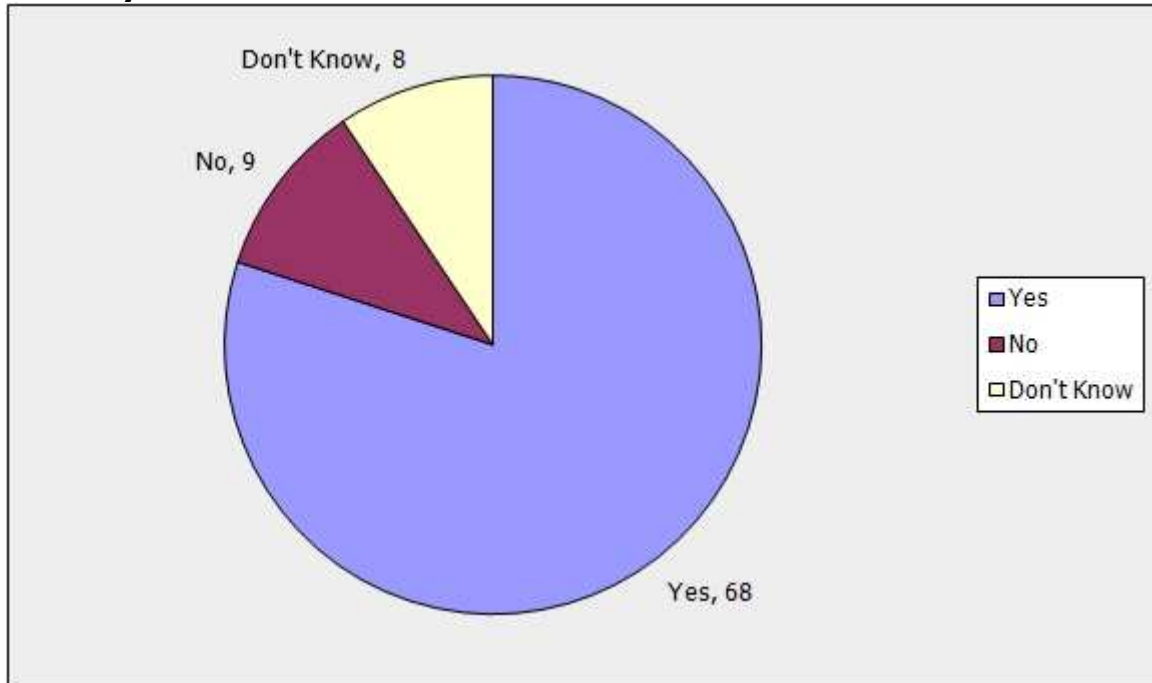


How safe do you think nanomedicine is? (1 = Not safe at all; 5 = Very safe)

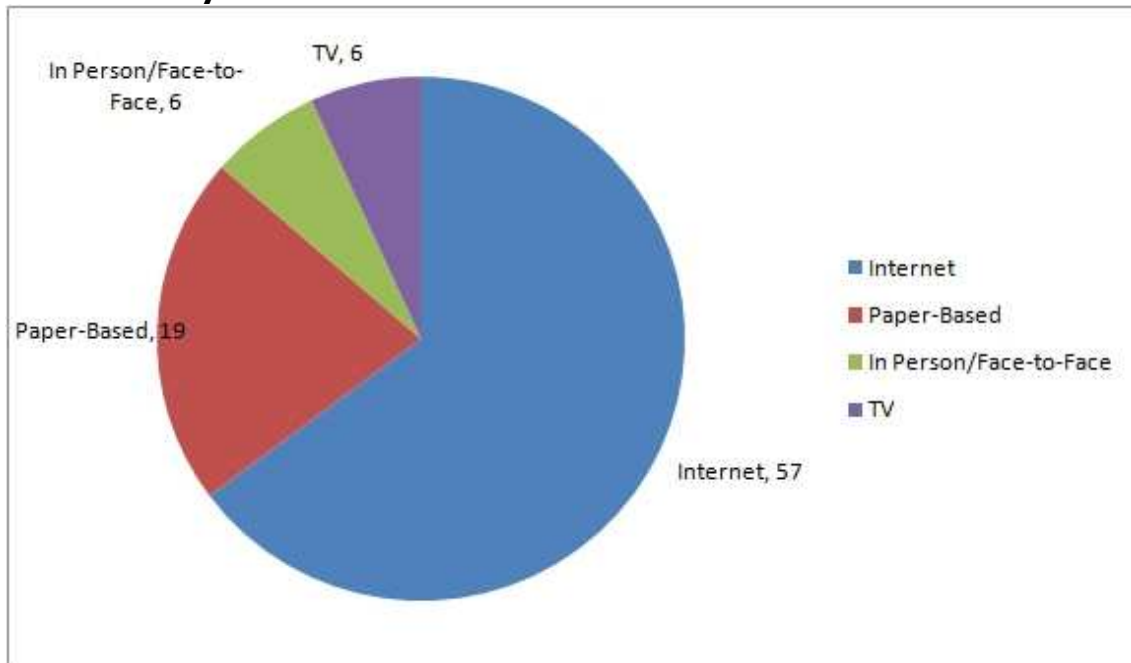


Nanomed Round Table

Would you like more information on nanomedicine?



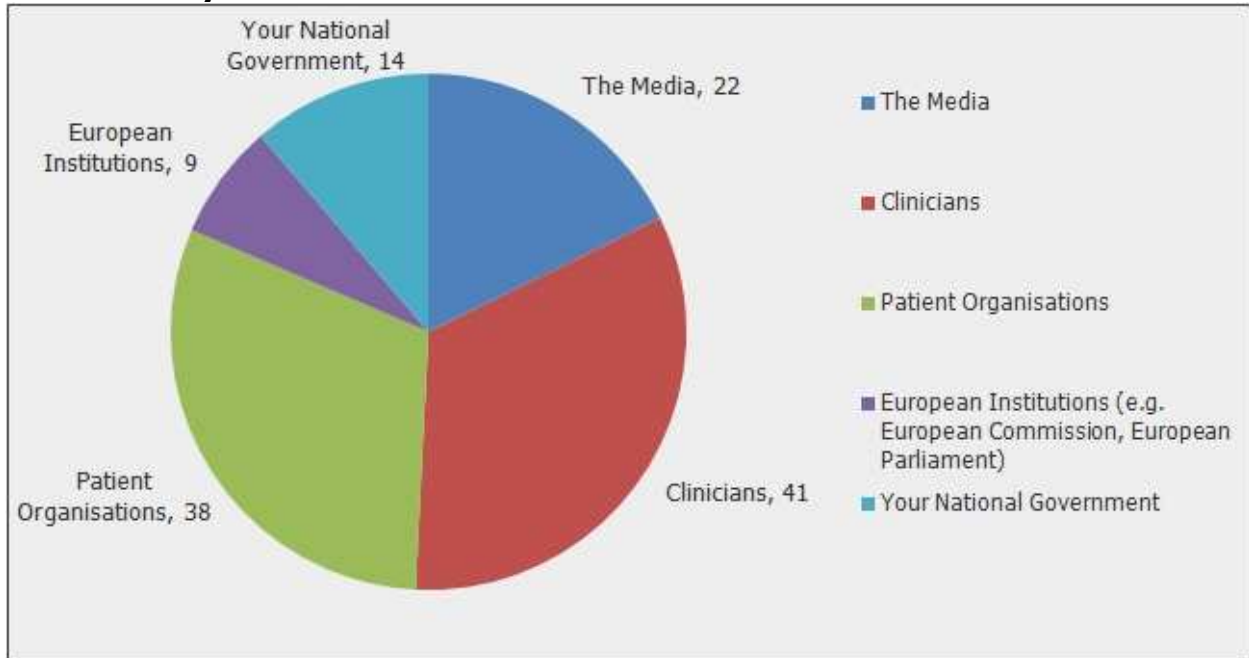
How would you like to receive this information?⁴



⁴ Respondents were able to choose more than one option, so responses total more than 100 per cent.

Nanomed Round Table

Who would you like to receive this information from?⁵



⁵ Respondents were able to choose more than one option, so responses total more than 100 per cent.