



ROADMAP

**The most important outcomes of
Alzheimer's disease and dementia**

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www.roadmap-alzheimer.org

Section 1: Brief descriptions of the findings from our individual projects

Section 2: Bringing together the findings from all of our projects

Section 3: Summary of our findings and next steps

Section 1:

Brief descriptions of the findings from our individual projects

Overview: Systematic review

All published
research
**What matters
most?**

Evidence base
included surveys,
interviews, diaries,
focus groups

People with
Alzheimer's, their
supporters and
health professionals

**32 outcomes
7 categories**



Overview: Consultations and interviews

Hear the lived experience to gain new insights and understanding

Disease progression, staging severity of dementia, meaningful delay

9 people with dementia,
7 supporters,
13 health professionals

60+ outcomes
7 categories

Which outcomes indicate that the disease is progressing?

People with dementia

Language use,
multitasking,
concentration

Supporters

Memory problems,
getting lost in
familiar places



Cognitive abilities

Overview: Surveys

Collect data from
a large number
of people

108 supporters, 44
people with
dementia, 238 health
professionals

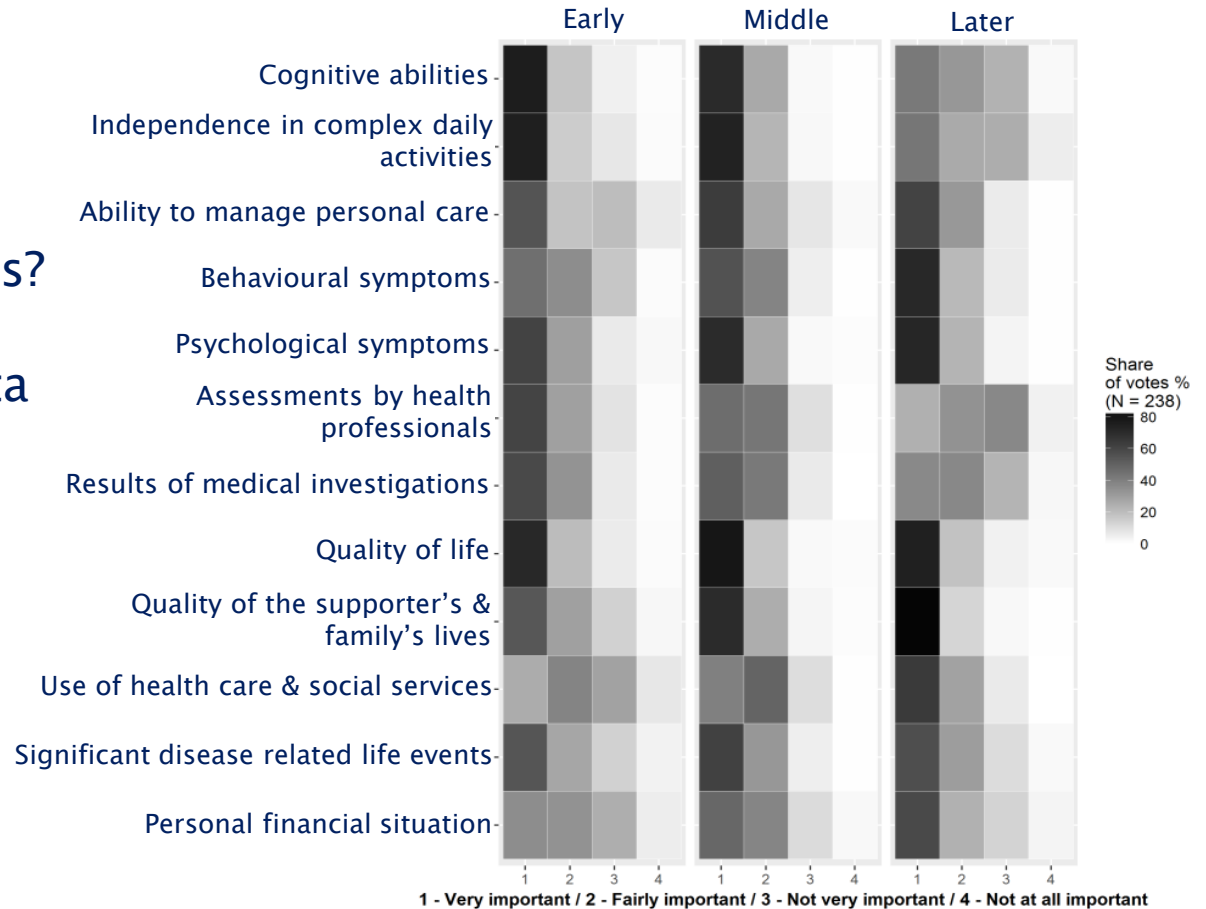
Ranking categories,
which are most
important?
Across disease
stages?

6 categories

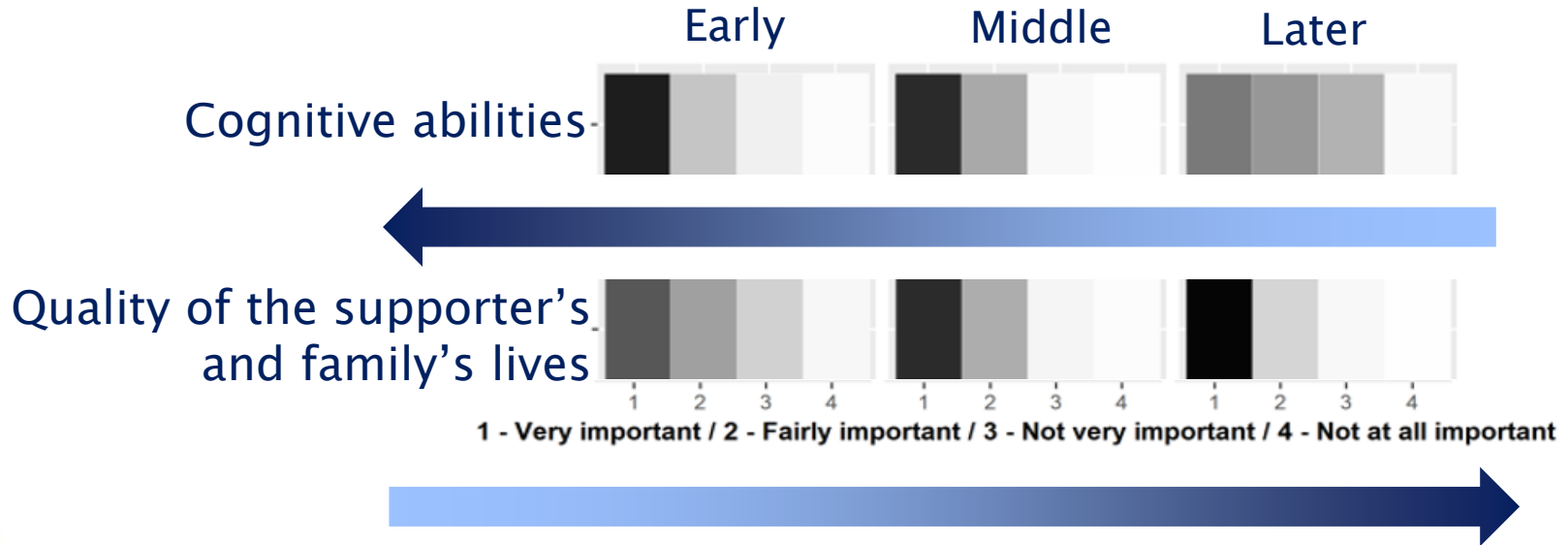
Example output from stakeholder surveys

How important is each category in the early, middle, and later stages?

Health professional data
(n = 238)



How important is each outcome in the early, middle, and later stages?



Section 2: Bringing together the findings from all of our projects

Integrating results

How did we do it?

“The combination of findings from two or more rigorous approaches provides a more comprehensive picture of the results than either approach could do alone.” – Triangulation



Categories: The main connecting points

The categories with the most evidence across all projects were deemed priority for the related participant group

Review

“She's my mother still. I don't see her disappearing. I don't see her personality melting away, you know, it's still there and that's hugely important to me”
Daughter of person with Alzheimer's disease

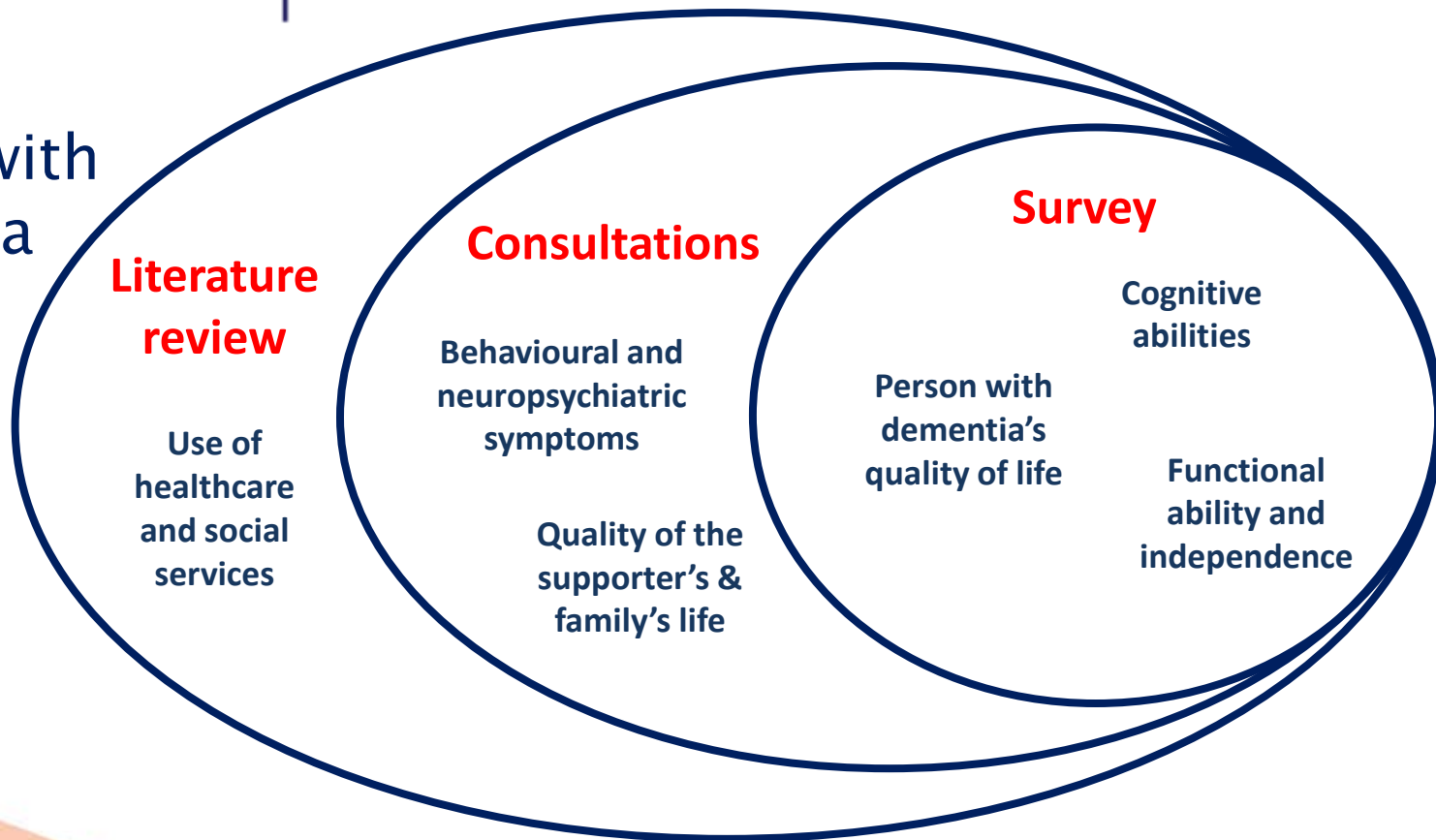
Consultations & Interviews

“Things like anxiety, being able to handle sadness and dealing with those sort of things. They [health professionals] were saying that it's definitely linked to the dementia.”
Person with dementia discussing mental health issues

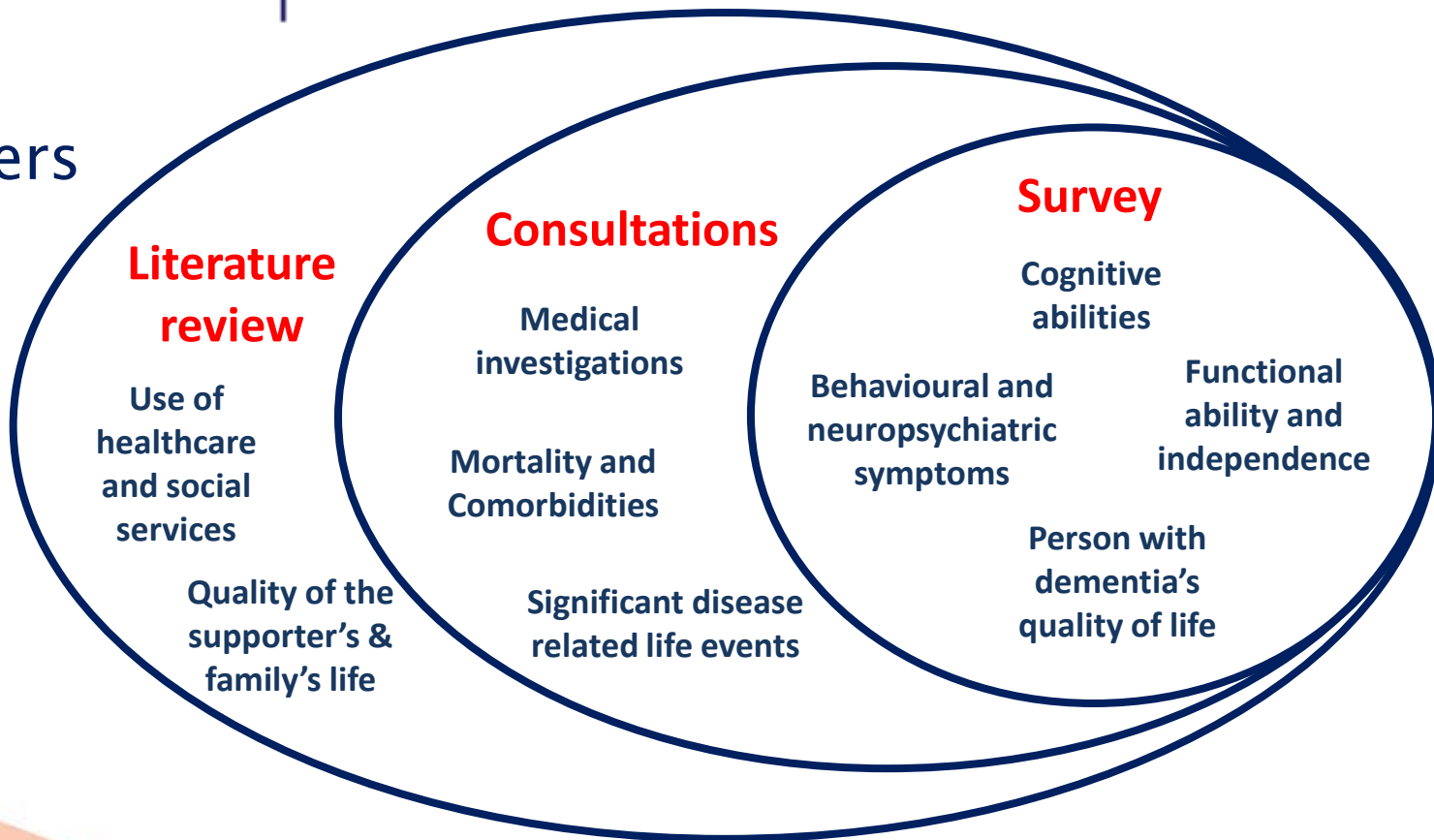
Surveys

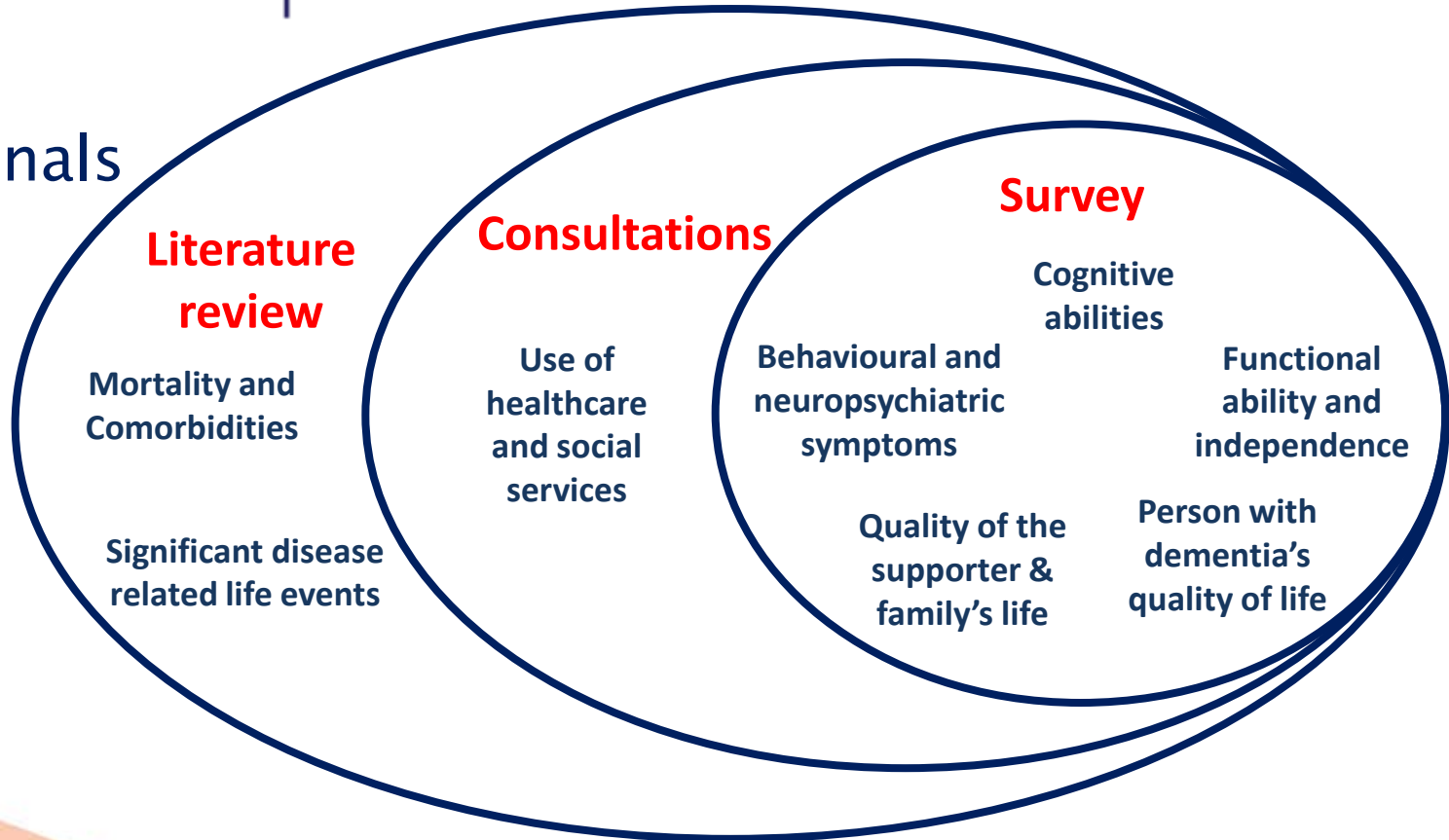
Priority for supporters and health professionals. Most votes for importance in the later stages of the disease (51% in early vs. 72% in later)

People with dementia



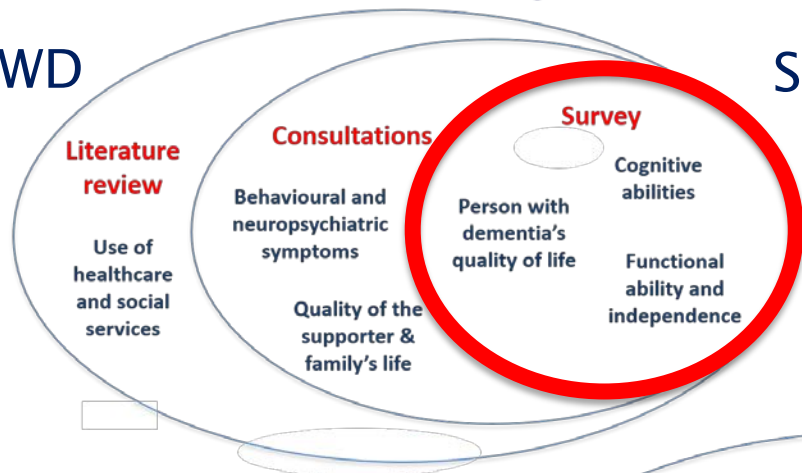
Supporters



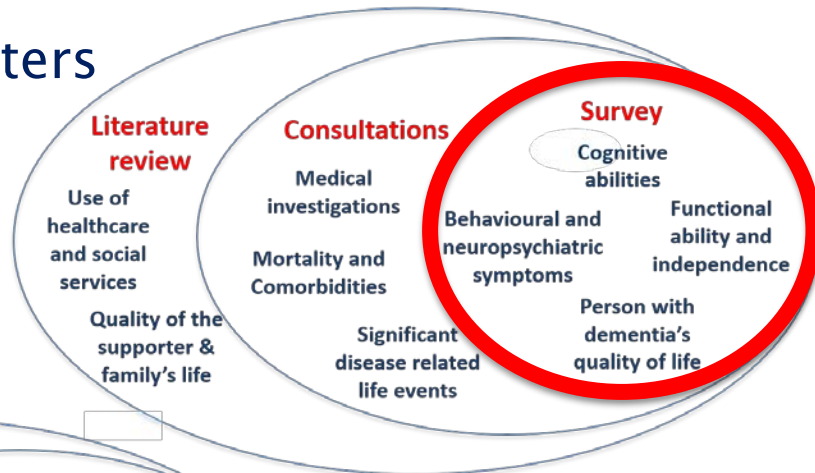
Health
Professionals

Overlap of categories across projects

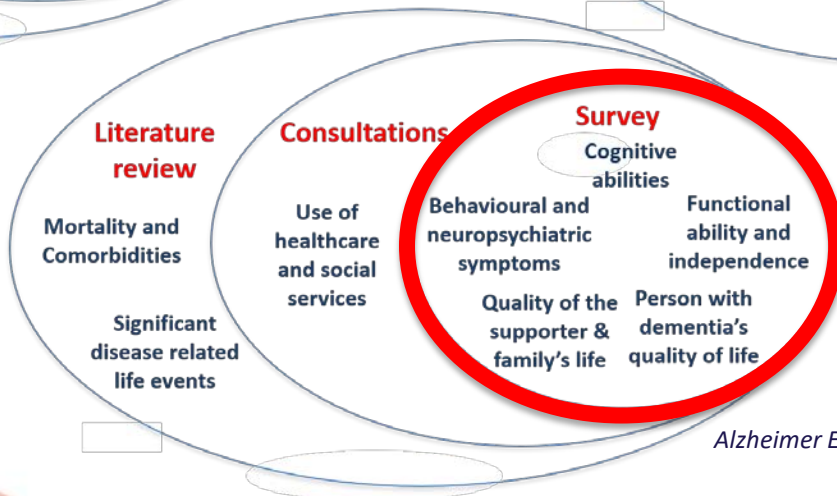
PWD



Supporters



Health professionals



Section 3: Summary and next steps

1 Our work emphasises the need to include the views of multiple groups to **get the bigger picture!**

2 Categories typically assessed in intervention trials, e.g. **cognitive abilities, behavioural symptoms** and **functional abilities** are priority to key stakeholders

3 However, categories like **quality of life**, and the **impact of the disease on their family members and supporters** are also priority to key stakeholders

Hopes for the future

By knowing what is priority to those affected most by the disease

