1. What is disease disadvantage?

**Delayed or misdiagnosis**

The diagnosis failures are a Systemic Disadvantage

The system seems to be set up to let people down, with multiple delays, misdiagnosis and refusal to take symptoms seriously.

“Keep going to your GP. You have to shout loud.”

**Life on hold**

Hamster wheel of treatments

Life is effectively on hold as seemingly endless rounds of treatment, scans and retreatments become a reality. It is often impossible to commit to any plans or live a normal life due to repeated, painful and uncomfortable hospital trips.

Scanxiety

A big part of the trauma of this rollercoaster is the inevitable fear of recurrence – as the time for another scan comes round, patients are fearful and anxious – it’s another attack on their mental health, already vulnerable through self stigma.

“Scanxiety, you know what’s coming, you get a bit more snappy, more anxious as the date gets closer.”

**Lack of bladder cancer knowledge**

A natural reluctance to talk about private bodily functions in public. Bladders, urination, incontinence, sex organs are all intensely private.

Men and older patients in particular, want to keep this to themselves – it’s not common to talk about such private things.

The choice to hide

Some patients want to regain ownership of their lives and their bodies. They have a desire to portray normality to the world – to protect yourself and also save yourself from the awkwardness of others.

Peer support and information

For some patients and caregivers there’s a lack of information about how life will be different afterwards. The value of patient support groups and networks is evident.

“Why do you have to collapse in the ER before people take you seriously?”

“No-one likes talking about their bits.”

57% of patient respondents say their mental state has negatively impacted the relationship with their partner.

43% of patient respondents say their mental state has negatively impacted their relationship with their partner.

61% of patients want a change in support and advice for carers

61% of patients want a change in the type of information

59% of patients want a change in emotional/psychological support

57% of patients felt the opportunity to talk to other bladder cancer patients was important.
2. Experience of internal stigma

A fear of being judged

Self-stigma is a significant issue for patients as they often anticipate and believe that others will judge them.

Patients resonated with the following statements:

- **26%** I don’t think many people even know what bladder cancer is
- **22%** I sometimes blame myself for my illness
- **21%** Sometimes I feel ashamed
- **21%** Society treats people with bladder cancer worse than people with other cancers
- **21%** I feel judged sometimes

Experience of stigma and disease disadvantage have less impact on older patients

- **75%** Aged 18-39
- **44%** Aged 60+
- **71%** Aged 40-59

Of the patients reported that bladder cancer had a severe or moderate impact on their lives.

3. Experience of external stigma

- **45%** of young patients felt blame from their family
- **43%** of young patients felt blamed by the doctor
- **31%** of patients feel that they have embarrassed their family, friends or colleagues by their illness

Making a difference for caregivers

Improving the lives of caregivers:

- Advice on how to help them manage their pain: **44%** Slightly agree, 88% Strongly agree
- Tips on how to talk to the doctors and nurses and what questions to ask: **55%** Slightly agree, 86% Strongly agree
- Training and advice in how to look after a cancer patient in general: **52%** Slightly agree, 85% Strongly agree
- Advice on how to keep them feeling positive and avoiding depression: **45%** Slightly agree, 85% Strongly agree
- More time to look after my partner / child / parent / friend / relative: **43%** Slightly agree, 83% Strongly agree

23% of caregivers have been diagnosed with depression or anxiety.