Senate Council Meeting 21 January 2016 The Citizens' Assembly Response

'What is Important to a Patient and Their Family/Carers and What Would They Want to Know When Confronting a Complex or Major Surgical Intervention, Particularly at the End of Life?'

What Patients and Carers Say

- Ensure that patients and carers understand the risks and benefits of options available – orally and in writing, in understandable language
- Have an opportunity to discuss the risks and benefits of surgery with the surgeon, and have the time to discuss concerns with a specialist nurse or support group
- Give links to appropriate websites to support information given

What Patients and Carers Want to Know (1)

- What would happen if the surgery does not go ahead?
- Are there alternative minor surgical procedures that could be of benefit?
- Where is the operation taking place and who will be operating?
- What are the success rates for the surgical intervention (of that particular surgeon)?
- What are the post-op infection rates of that hospital and surgeon?

What Patients and Carers Want to Know (2)

- What will be the immediate post operative effects?
- How is pain managed/will it be able to be managed?
- Will family/carers be able to stay with patients in hospital/how will they get to the hospital/is financial assistance available if they do not have their own transport?
- How long will the patient be in hospital?
- What support is available if the patient returns home/does the patient need support to get her/his affairs in order?

What Patients and Carers Say – General Points

- Healthcare professionals must be honest with the patient/carers about the comparative risks and benefits, giving examples of quality of life/length of life possibilities for different courses of action. Is the surgery worth it, given the variables present in each case?
- Decision-making about surgery (or not) must be a joint one with patients/carers and the professional team.
- The dignity of the patient must be maintained
- Patients/carers need to be kept well-informed throughout of treatment plans or any changes to previously agreed actions