



Use of tumour materials for research: Parent`s perspective

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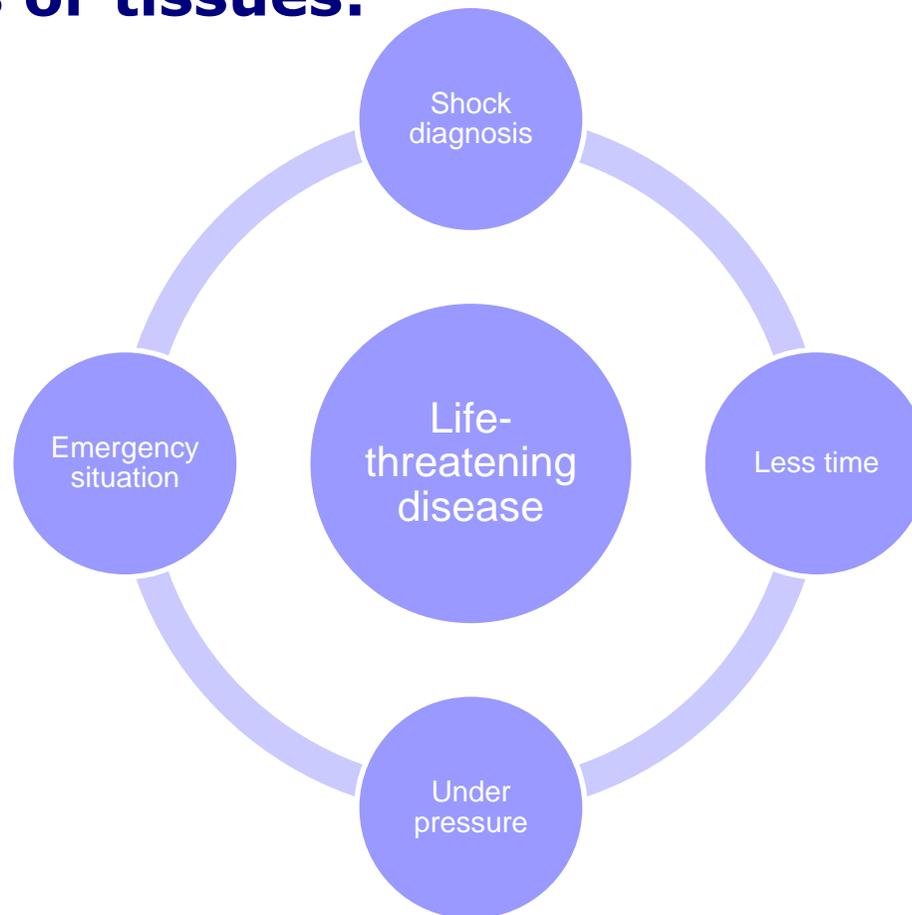
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How is the situation for parents, when they have to give consent for the treatment of their child and use of tumour materials or tissues:





Parents` point of view towards research:

- Supportive towards research
- Now 80 % survival rate – this would not be possible without research
- Cautious about research performed by private companies → being transparent about the research category (academic or private)





How is it for parents when they have to give continuously consent for their minor child:

- Family has their “normal life”:
 - e.g. different emotions come up (fear, worries, fault ...)
 - e.g. this leads that the past is still topic within the family
- Don't understand the technical details of research projects → through away the letter





What are the wishes from parents` side towards informed consent (2/2):

The **basis** for this is - **INFORMATION beforehand:**

- To be informed that the data/tissue of their child will be used for future research and
- To be informed about the conditions under which their data/tissue will be stored

Long-term wish/vision from parents` representatives:

- Involve trained and educated parents` /patients` representatives in Ethics committees
- Ethics committees should act as a gatekeeper – protecting people against `unsuitable` research projects

