Cancer Information Needs in Germany
Lesson learned from a population-based study
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Lessons learned from surveys of the German Cancer Information Service

**KID User Survey 2011**
Questionnaire survey of KID hotline users. Response rate: 78% (n=3658)
Patients 55%, Family 33%, Interested Public 10%

**Population-Based Survey 2010**
Population-based face-to-face interview survey
2247 participants (of these, 360 cancer patients)
(Prognos AG and Institut für Demoskopie Allensbach)

**National Survey of Health Professionals 2011**
Questionnaire sent to 2,920 health professionals: Response rate 14-41%

**Survey of European Cancer Information Services 2010/2011**
Questionnaires sent by KID to 32 European CIS’s. Response rate 90%
Short online survey, sent by ICISG to 85 global CIS’s. 27 responded.
Population-based Survey: Interest in Information and Participation

60% want to know “possibly everything” if they get cancer (women 65%, higher education: 68%)
Over 50% want to participate in decision making (65% of patients)

- 40% need information about cancer (Patients: 60%, General public: 35%)
Cancer Information Needs in Germany
High expectations on cancer information delivery across groups

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Population-based survey:
- Higher education: independent, evidence-based information; active search
- Lower education: information free of charge, short, precise, comprehensible; rather random uptake
- More than 2/3 of all participants (100% of participating patients) have previously searched for cancer information once or more often. 40% have open questions about the obtained information (patients: 60%, general public: 35%).
- Only 1/3 of all participants considered previously obtained information as helpful