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Following up Adults with Achondroplasia: Is it Necessary?

Florian Innig (BKMF e.V., Germany)



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Conflict of interest:

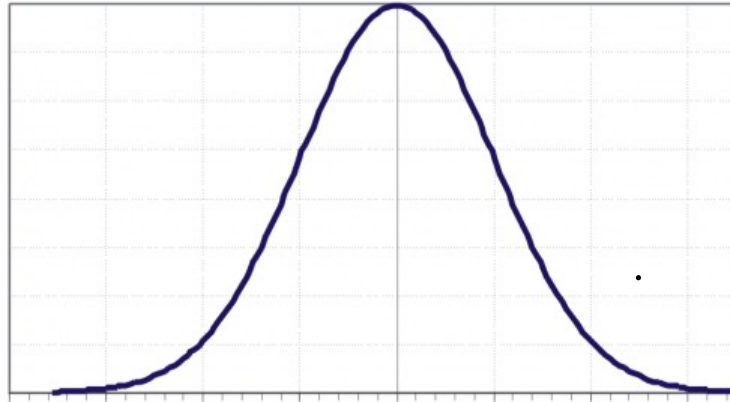
- None

General comment:

- We all have a bias in our perception



- Who am I going to talk about?



- Neither severely affected individuals, nor paralympic athletes
- Is there an issue we need to talk about?



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Survey among Patients

Survey by EuRR-Bone & ERN BOND

Inês Alvez (Portugal), Florian Innig (Germany)

Support by Ana Priego, Leiden University



ERN BOND
EUROPEAN REFERENCE NETWORK
ON RARE BONE DISEASES

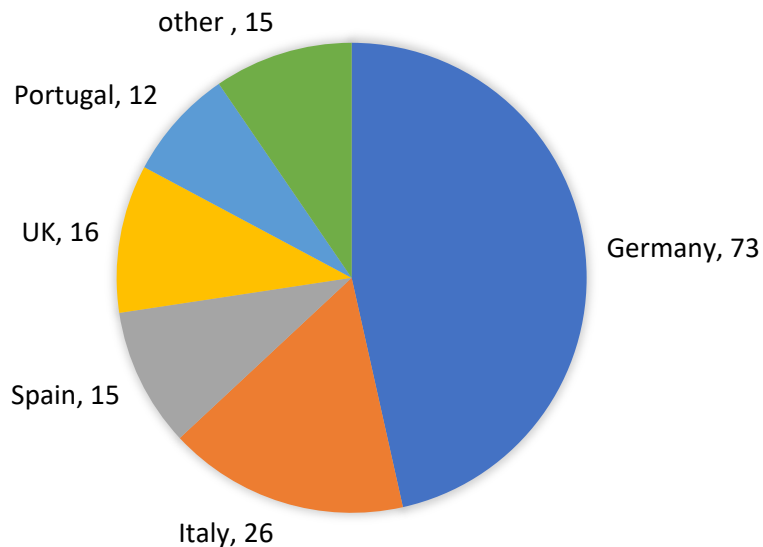


EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions

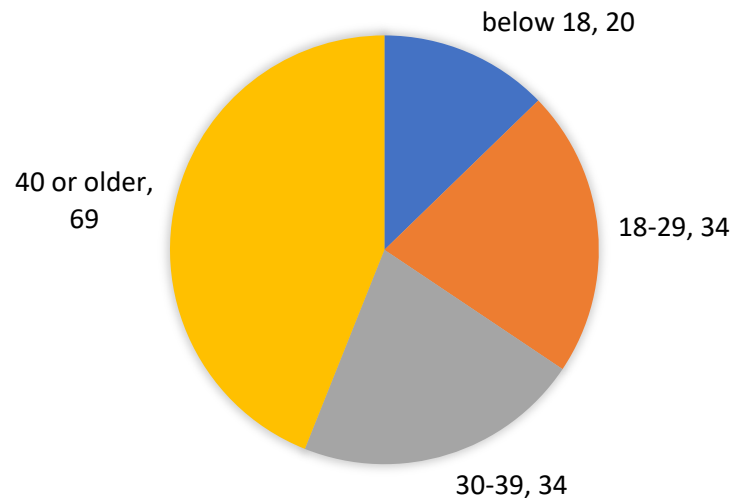
Collective of the survey

- 157 responses
 - Responses from 13 countries

origin of participants



age distribution

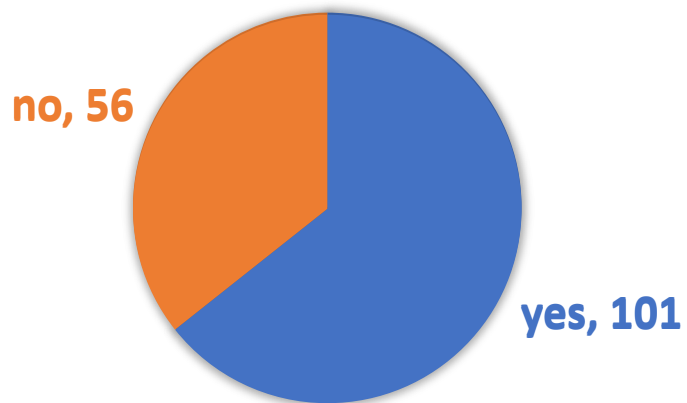




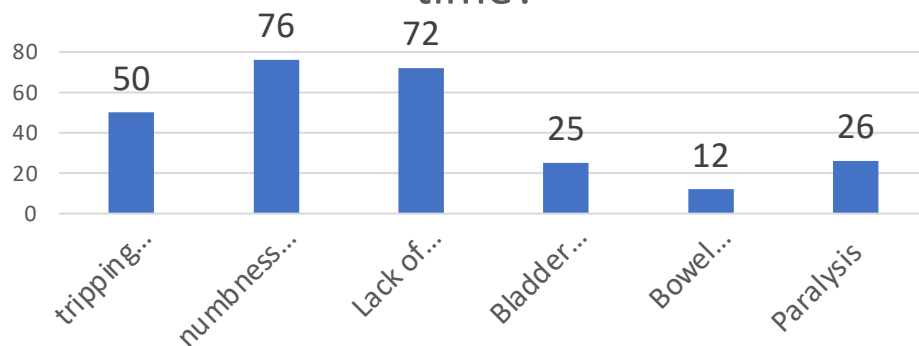
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Spinal symptoms

DO YOU HAVE ANY SYMPTOMS?

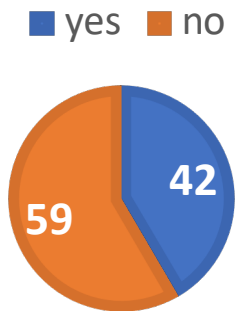


Did you ever experience any of the following symptoms in a significant way over a continuous time?

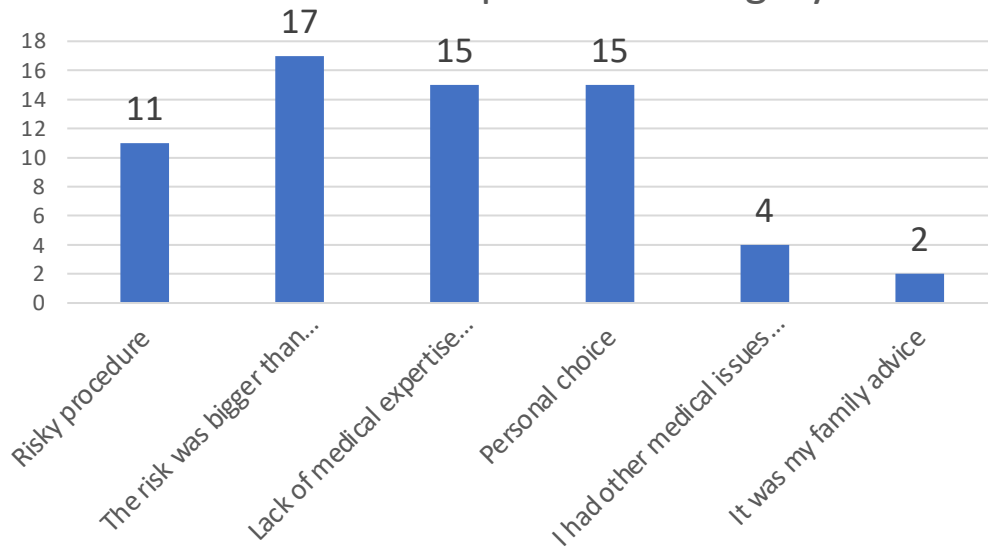


Closer look into the treatment II

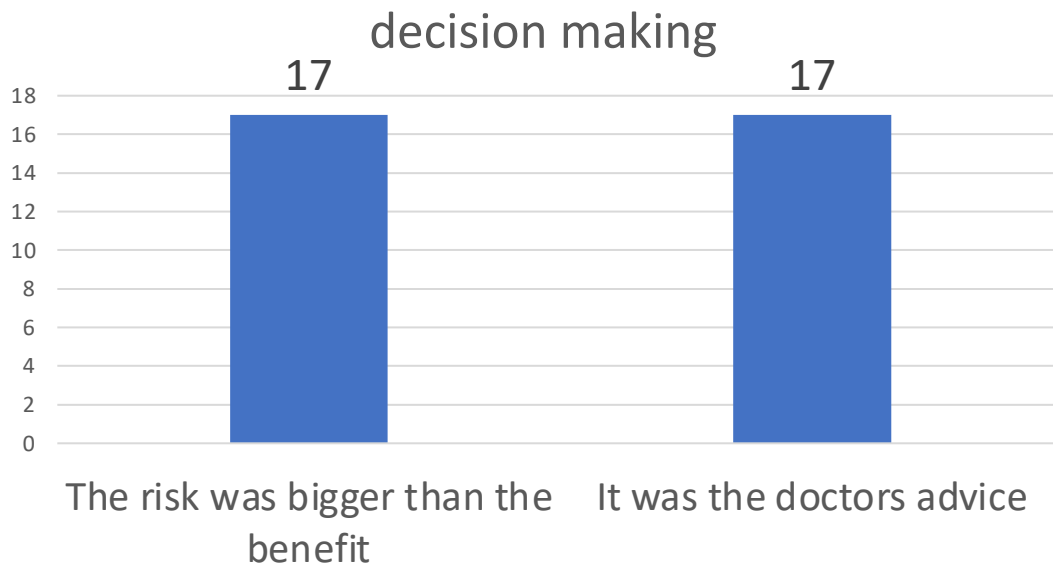
DID YOU UNDERGO A SPINAL DECOMPRESSION SURGERY?



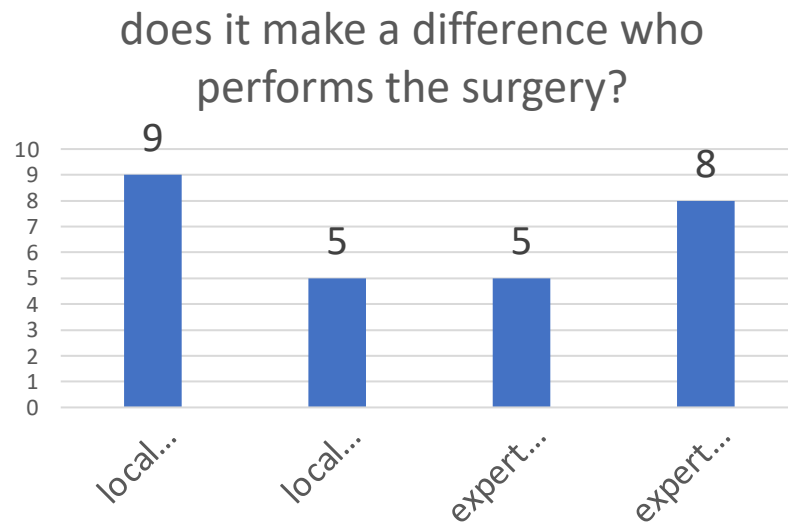
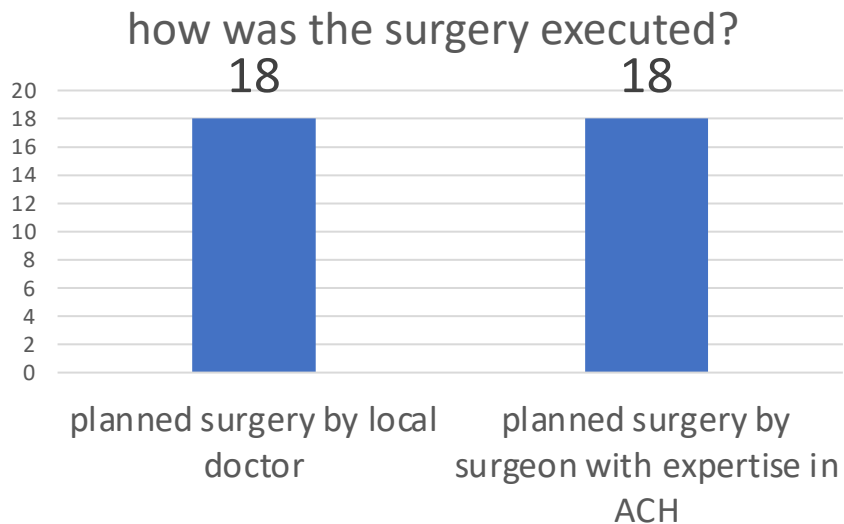
reasons not to perform a surgery



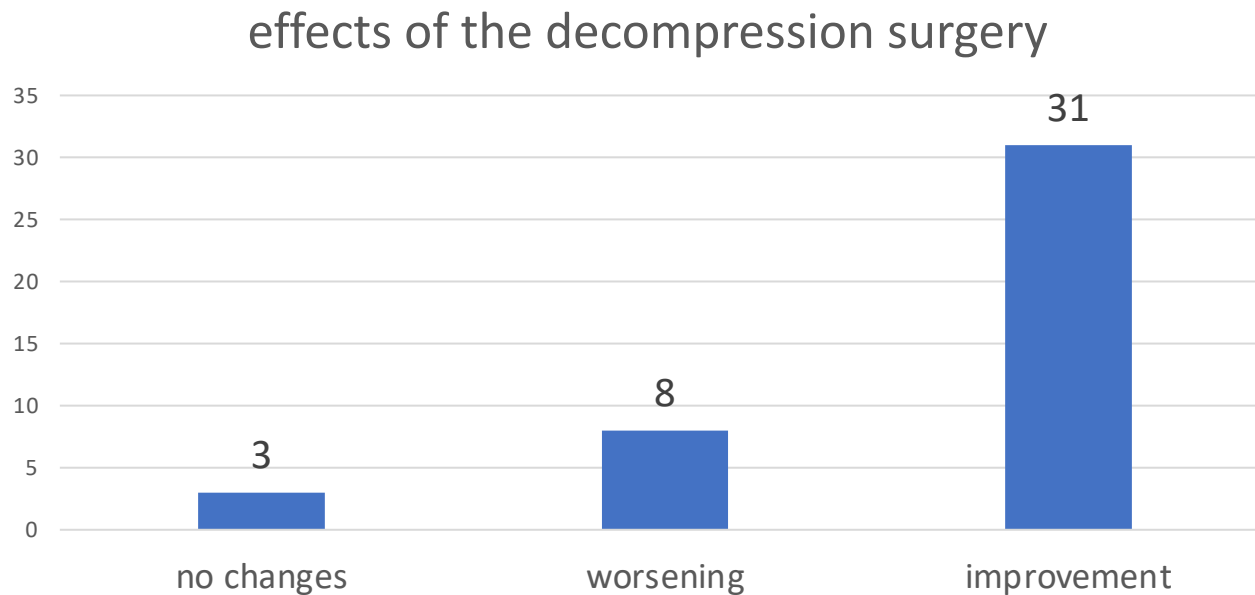
Closer look into the treatment III



Closer look into the treatment IV



Impact of a spinal decompression





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Health issues are the same in every country

Yes, there are issues we need to talk about!



Challenges

- Evidence is limited
- Adherence of routine check-ups
 - High in young children 95%+
 - Decreases over time (youth exams 12-14 years down to 43%)
 - Cancer routine checks – 95% believe that they are useful, 42% fear getting cancer, depending on the screening between 20% and 67% don't go
- Experts and medical expertise in adults are limited
- Possible solutions need to be adapted to local systems

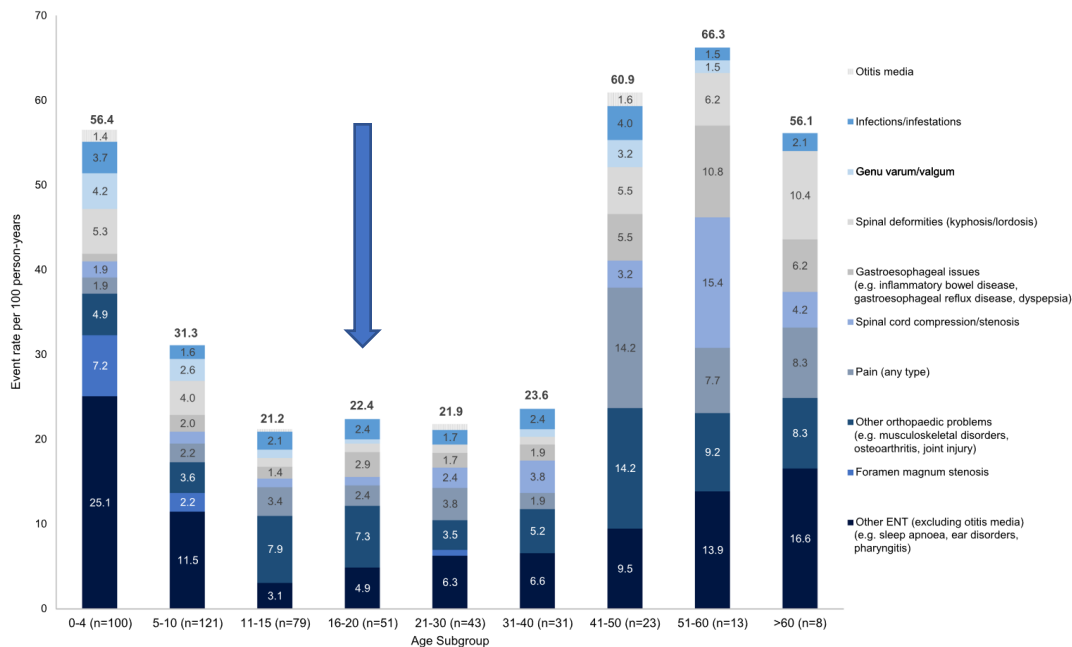


Fig. 1 Burden of medical and surgical complications by age at time of event. Each patient may have several complications reported across the lifespan and may therefore be included in multiple age subgroups. Event rates per 100 person-years were calculated as the number of events divided by the total number of patient historical years, multiplied by 100. ENT Ear, nose and throat



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What can we do?

- A follow-up needs to be meaningful
- We need
 - Inform people on medical issues in adults
 - Inform people to make better choices
 - Better decision making processes in the doctor/patient relationship
- Focus on spinal stenosis
- Drive home the message
 - If you have symptoms of spinal stenosis do (fill-in country-specific solution)
- How do we reach people?
 - transition talks, word of mouth, role-models within the community, support groups



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Thank you very much for your attention!

EAFF

European Achondroplasia Forum

