



Report for consultation with young persons: KidsBarcelona FSJD

**Edited from presentation at Joint
workshop between WP1 & WP2**

In Brussels, 11 October 2018

Introduction

- Online survey may not be the most adequate method for understanding the views of some patient groups.
- Some patients may have some specific needs that have to be considered and addressed.
- People with dementia and children and young people could be used as examples of patient groups for which, in some cases, a different approach or different issues need to be considered

METHODOLOGY AND APPROACH USED

KIDS BARCELONA

- Set up in 2012. Composed by young people from 12 to 18 years old. 17 members. 80 % patients, some of them with experience as participants in clinical trials.
- Monthly meetings (Friday late afternoon) during 3 hours.
- Every session has a facilitator and the involvement of a clinician or researcher.
- Founders of eYPAGnet. Network with the recognition of category 4 of EnprEMA.



APPROACH

- Meeting in Barcelona- 28th of September
- Information about the session sent to the young people in advance
- Introduction about the project and about medicines development was given by the Coordinator of the Clinical Trials Unit.
- Participants: 12 young people
- 2 facilitators from FSJ
- Topics explored:
 - Understandings of PE, views on PE in medicines development within the paediatric setting
 - Work in 2 subgroups, each group focused on one of the 2 decision making points (specific vignettes were developed to facilitate discussions)
- The meeting was audio recorded, notes taken on flip charts and summaries created by rapporteurs

KEY FINDINGS



MAIN THEMES

Enabling engagement:

1. The voice of the person living with the condition.
2. Myths and misconceptions.
3. Accessibility and reasonable accommodation/adjustment.
4. Information and training/ induction
5. Personal support.
6. Guiding principles: promoting autonomy, respect and equality.

Financial aspects

The voice of the person and misconceptions

- The only way to include the voice of young persons in medicines development is allowing their contributions as patient experts always when it's feasible.
- Is not the same than involve parents, because experiencing a disease in first person is very personal.
- If young persons receive the right training support they can contribute like the adults patients have for a long time.
- The training/help of other young expert patients can be considered part of the preparation requested for every engagement activity in medicines development.

Accessibility / accommodation

- The support of the facilitator of the Young Persons' Advisory Group (YPAG) makes the process of involvement easier.
- Meetings outside of the school schedule are more desirable. The use of teleconference system will avoid the need to travel.
- In some activities (international projects) the language can be a limitation in order to contribute with quality and to reduce the level of stress.
- The value of the group activities always is better than the involvement of individual patients.
- The language and the format of the activities need to be adapted to young patients

Information and training

- Training or specific preparation needs to be mandatory in order to ensure that the young people can contribute with the right background.
- Hospitals (where clinical trials happen) and patients organisation (“who work for my rights and to improve the research of my condition”) need to be the responsables to ensure the right information and training.
- The knowledge and expertise clinicians can bring to young people is very valuable.
- The use of new technologies (vídeos, games, etc.) facilitates the training process.

Personal support

- Facilitator of the YPAG is the right personal support to prepare the involvement in a specific activity or to support the young person while they are contributing.
- YPAGs, where a young patients are involved as a group, is better than the individual contributions.
- Educational material and information need to be adapted to young patients.

Guiding principles

Autonomy

- Ask the person what he/she needs and what their preferences are.
- “If I have the right information/education I can take the right decision.”

Respect

- For young persons, it is invaluable to know that they can help future patients through their contributions in research projects that aim to design better medicines for children.

Equality

- We have the same rights than adult patients. We have the capability to contribute in research initiatives.

Financial aspects

- All costs need to be reimbursed.
- Payment for the young person's time can lead to a bias to participate. Some teenagers will say "yes" even if they are not well prepared to contribute if they know they will receive a compensation.
- Other ways of compensation can be explored: eg. voucher, music tokens, etc.
- The outcome of our involvement is also a way of compensation.

Conclusions

- Main learnings:
 - Patient involvement with young people is feasible but training and support is required.
 - The outcome of my involvement is a reward that not always is offered in return to the patients.
 - Preference to be involved in a group and in individual way.
- Gaps
 - No experience in HTA with the involvement of young people.
 - Limited experiences around Europe. Stakeholders need to consider that young people are able to contribute in first person.
- Issues not addressed in the consultation (e.g. sustainability)

Thanks

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