Take home messages...
What is fair research (for children)

Questions anyone involved in research should ask.

1. Is there justifiable purpose?
2. Is the study built on what is known already?
3. Will the study provide meaningful information (information of value)?
4. Will the method provide valid information (that we can trust)?
5. Is the research team equipped to complete the study?
6. Does the research incorporate public, patient and participant views?
7. Is selection fair? (inclusion / exclusion)
8. Are participants recruited fairly?
9. Is there fair balance of benefits and harms for all with an interest?
10. Are participants offered a fair choice (informed consent)?
11. Is personal data handled appropriately (confidentiality)?
12. Are there fair payment and recompense for injury?
13. Once finished do participants receive acknowledgment and appropriate care?
14. Will the project be registered and results placed in the public domain?
Patient Engagement at EMA

- European network of paediatric research at EMA (Enpr-EMA) -> expertise in performing paediatric clinical trials

- Patient representatives are involved in the work of Enpr-EMA, and different Committees (PDCO, PRAC, CAT, COMP)

- Patients, consumers and carers are involved in a wide range of EMA activities:
  - Eligible EMA patient organisations
Take home messages...

1. Make sure the involvement of children and young people in the drug development process is feasible.

2. PPI needs to be an integrated part of the process from the beginning.

3. Design, execution and evaluation of every PPI activity is essential.

4. Share your experiences of PPI (good and bad) so everyone can learn ‘how’ to effectively involve patients and families in the research process.

5. Showing the added value of PPI (in terms of outcomes/financially) is important for implementing points 2 and 3 below.
This Toolkit is intended as a living repository of educational materials to provide patients participating in clinical trials, their families and new YPAGs (Young Person Advisory Groups) with information to get started in patient and public involvement in the development of medicines.

In this section, patients and their families will find materials that will help them understand what a clinical trial is, what happens in a clinical trial, what ethical and legal implications entail and what role patients’ (and their families) can play in the development of a clinical trial.

*Click the panel below to access the complete educational resource bank.*
c4c resources

• c4c Educational resources: https://conect4children.org/educational-resources-library/

• c4c database for patient representatives: https://conect4children.org/patient-and-public-involvement/

• LinkedIn: https://www.linkedin.com/company/conect4children

• Twitter: https://twitter.com/c4c_network @c4c_network
Final poll

After this workshop, I plan to take action by....
Write your answer in the chat box
THANK YOU!
PPI team

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#conect4children
Congratulations to all of you!
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