

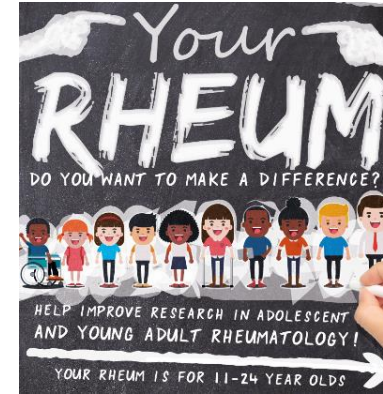
CAPTURE-JIA: Capturing the young person's perspective of routine data collection in clinics

Lunt L, Barton F, Wright C, McDonagh JE, McErlane F and Your Rheum members

CAPTURE JIA is a core dataset for Juvenile idiopathic arthritis (JIA), designed to collect complete information on disease outcomes, service delivery and research, at each clinic visit

Lunt, L.E., Shoop-Worrall, S., Smith, N. *et al* 2020

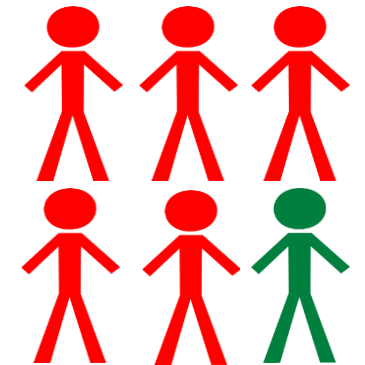
Objective: To collate opinions from young people regarding national patient data collection



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**6 young people
Aged 16- 21yrs**



Manchester
Biomedical Research Centre



NHS
National Institute for
Health Research

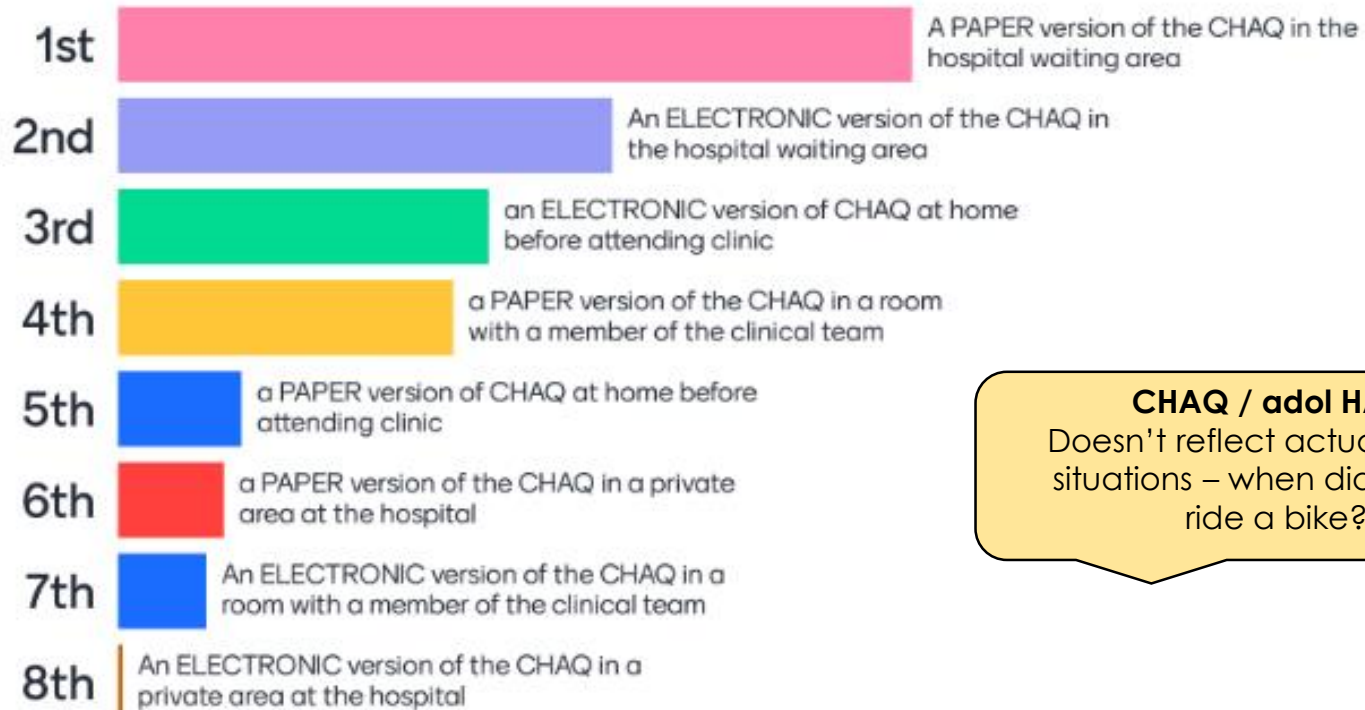


What did Your Rheum say?

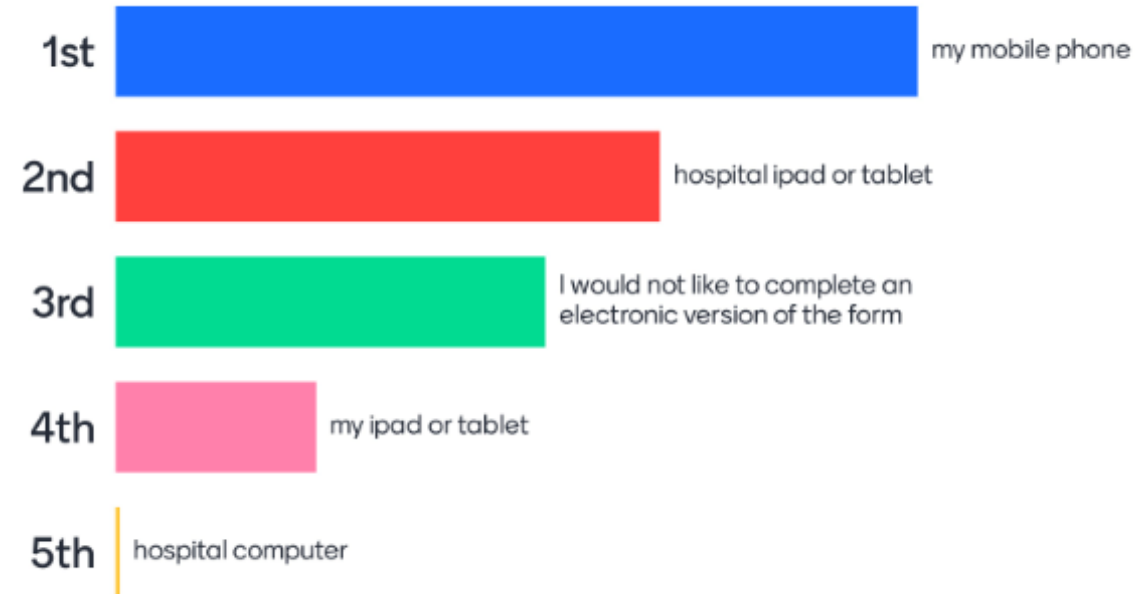
How do you feel about data being collected and analysed with the purpose of improving quality of care?

- Important – expectation this is already happening
- Anonymity essential

Rank your top 3 preferences of how you would like to receive questionnaires?



Rank your top 3 methods for completing an electronic version of clinic questionnaires



CHAQ / adol HAQ:

Doesn't reflect actual real life situations – when did you last ride a bike?

Current experiences:

parents asked to complete forms NOT young person.

Pain VAS: develop a

pain word map and circle appropriate words

Conclusions

- Analysing patient data important & expected
- Both paper & electronic data capturing methods are useful
- Complete questionnaires in the clinical setting
- Important to speak to & report from the young person directly
- Next steps: explore CAPTURE:JIA collection in AYA clinics

Thank you to the young people who took part