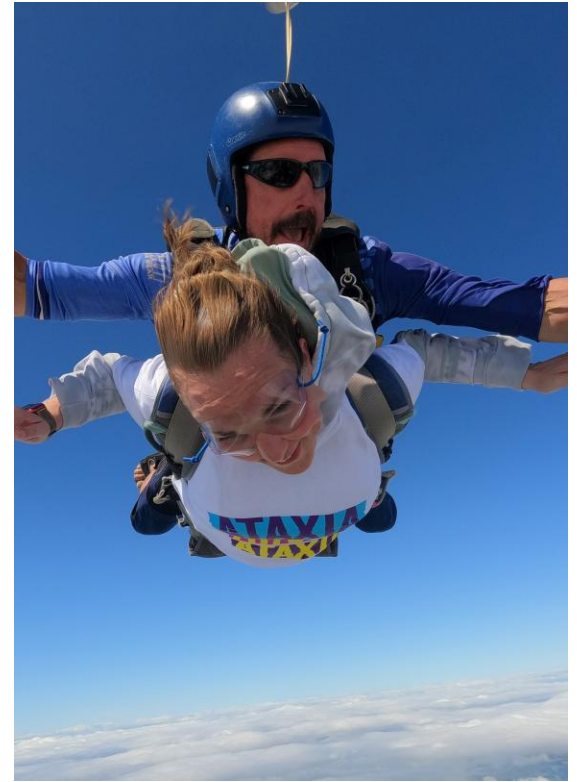


# ATAxia



60 years of supporting people affected by ataxia, and research into the ataxias



# If Ataxia Specialist Nurses are the answer..... What's the problem?

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- 49% 12+ months after GP visit to be seen by a neurologist (NNPE)
- 42% additional 12 months to be diagnosed. (NNPE)
- 28% completely understood the diagnosis explanation given at the time (NNPE).
- 74% felt lack of knowledge from GPs and primary care professionals. (AUK2021)
- 35% felt lack of knowledge from consultants or neurologists (AUK2020)



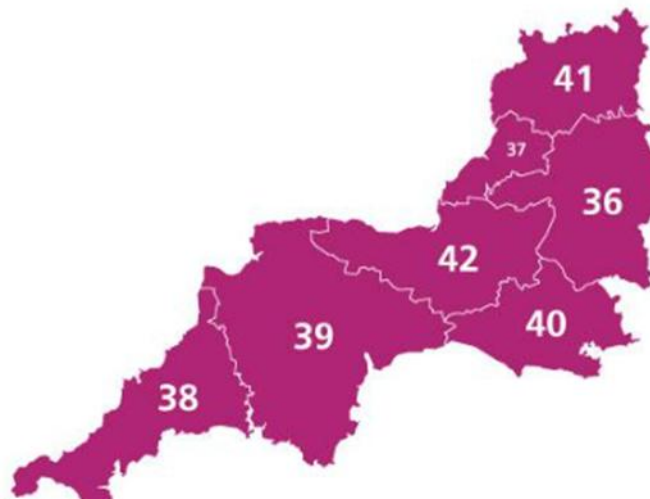
# If Ataxia Specialist Nurses are the answer..... What's the problem?

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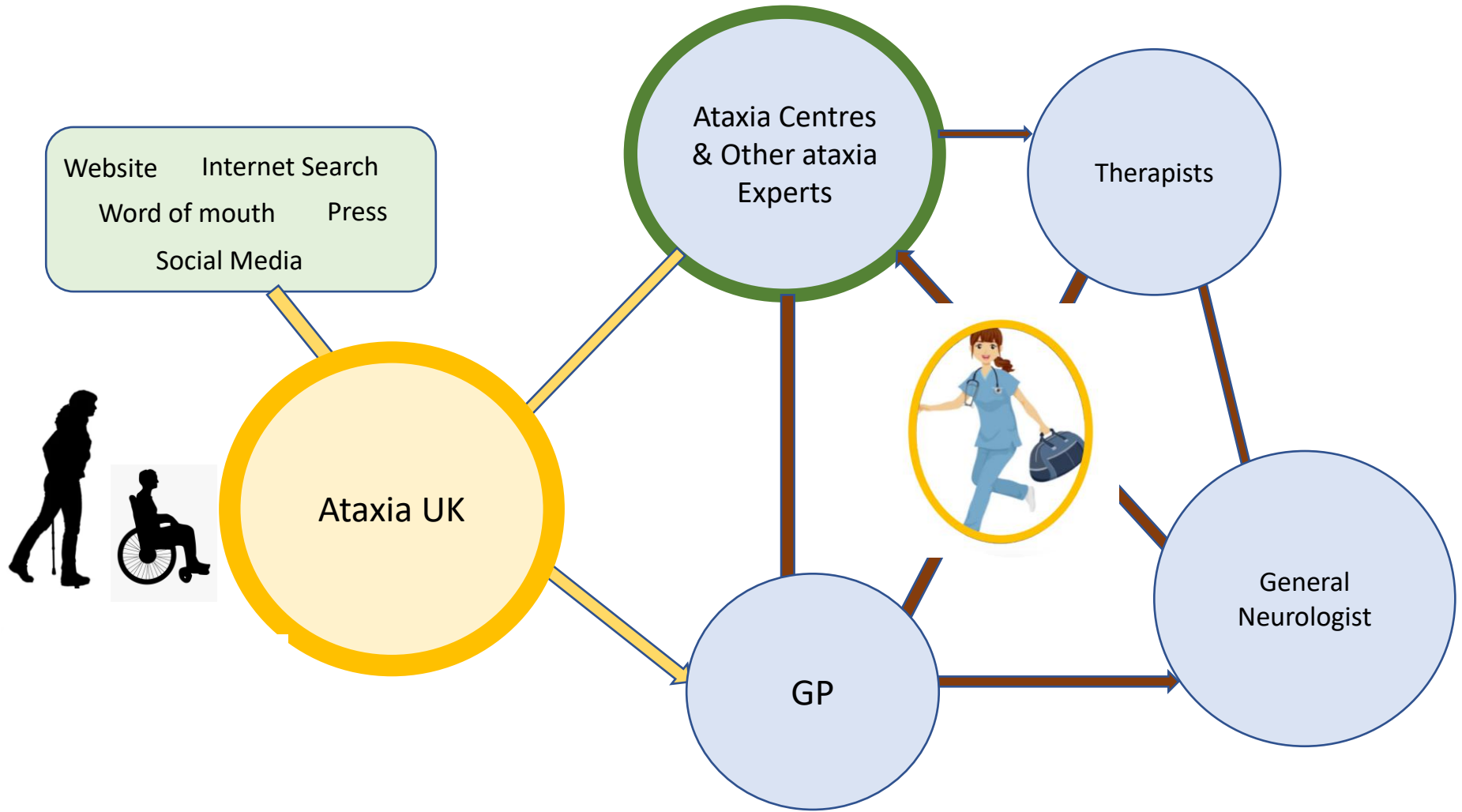
- 43% lack of information about ataxia and symptoms (AUK2021)
- 38% lack of practical support (AUK2020)
- 44% lack of emotional support. (AUK2020)
- 68% not asked re mental wellbeing by health/social care professional (NNPE).
- 28% had access to speech therapy which met most needs. (AUK2020)



ATAXIA



# Location of Specialist Ataxia Centres



# How will it work?


- Nurse supports patient in attending clinical appointments:
  - Preparation
  - Accompany
  - Debrief
- Nurse establishes legitimacy with neurologist
- Nurse invited into clinics by neurologists to support them
- Nurse supported by clinical and managerial supervision

# Benefits for people with ataxia

## Holistic service


- Information and explanation
- Support in attending neurology appointments
- Support in accessing joined up services
- [Once in clinic] support from the moment of diagnosis

# Benefits for local neurologists

- Nurse expertise in ataxia and educational role
  - Nurse links to expert neurologists to foster networking and advice to local neurologists
  - Nurse as conduit for information on new developments
- 



# What can Specialist Nurses Bring?

- Knowledge of, and insight into, the patient pathway/services available
  - High-level expertise in the care of a specific patient group.
  - Additional qualifications - meaning they can perform advanced tasks.
  - Nurse potential to find/engage people for trials/research
  - Knowledge of the patient organisation, partner organisations and other resources
- 

# Issues to be resolved

- Relationship between the nurse and NHS services
  - Exchange of information and GDPR issues
  - Protocols
- Size of caseload
- Selection of patients



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