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Patient Experience and Delivering Compassion

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Pelvic Pain Support Network

Insert image/s relevant to topic

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Disclaimer

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Background

European Society of Radiology: Patient Advisory Group

European Association of Urology: Chronic Pelvic Pain Guideline Panel member

IMI Paincare (TriPP) patient representative

Advanced Pain Discovery Platform: Advantage: visceral pain, Patient Advisory Board

USA/Europe: Patient experience 50 + years

Patient representative/advocate: policy, research, pain education and access to care/services

Personal experience

Multiple TVUS examinations and surgeries

50 years pelvic pain, no physiotherapy advice/intervention

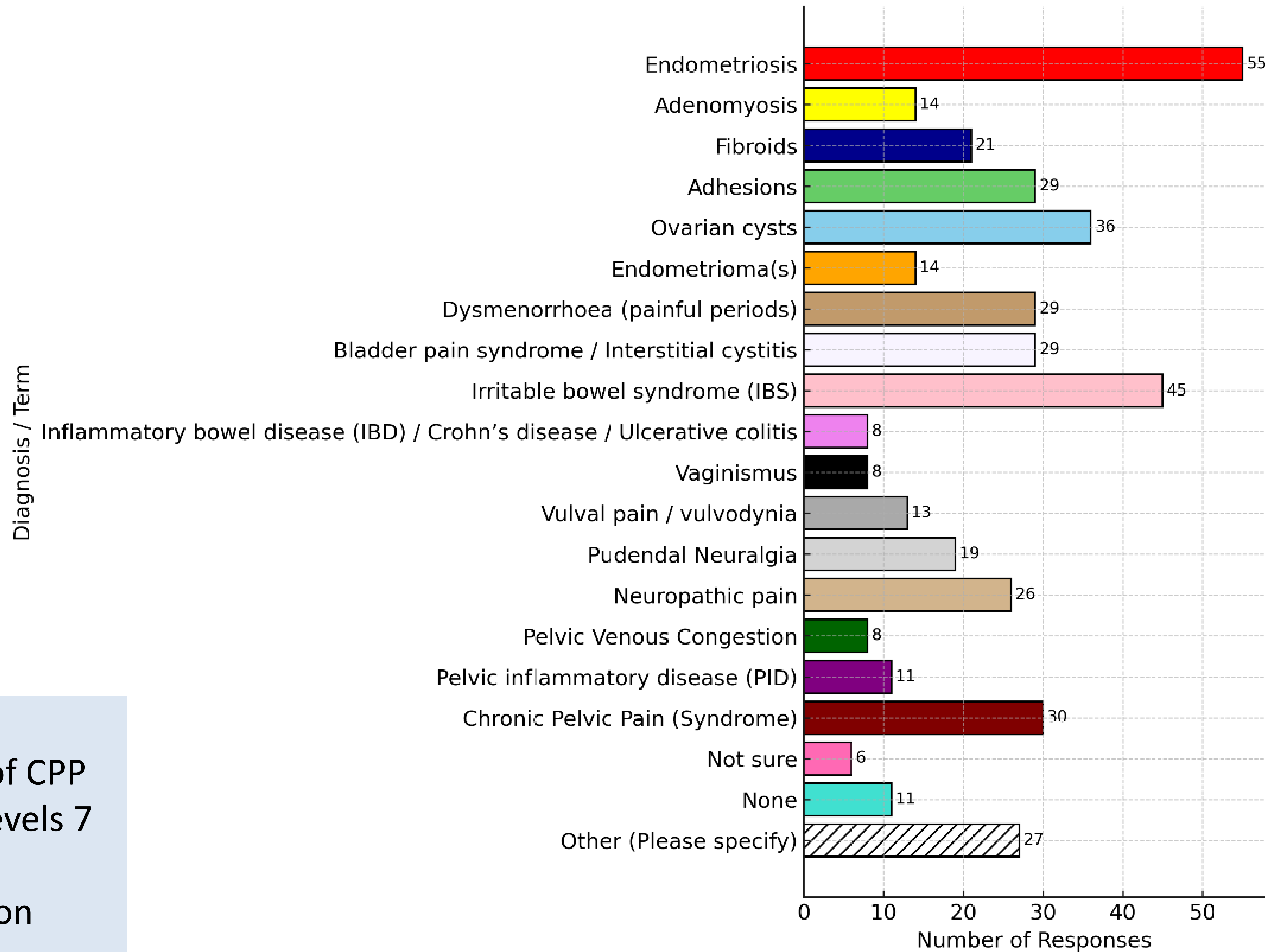
Advice ? surgeon   Advice ? GP

What did I do ?

Recent referral: Group Session Pelvic Health: continence, jumping through hoops to get a F2F appointment

Disjointed service, separate from pain: why ?

Recent Survey



- 172 UK females, age 18-80
- Most reported 12+ years of CPP
- More than 58% had pain levels 7 or above, about 40% had accessed physio intervention

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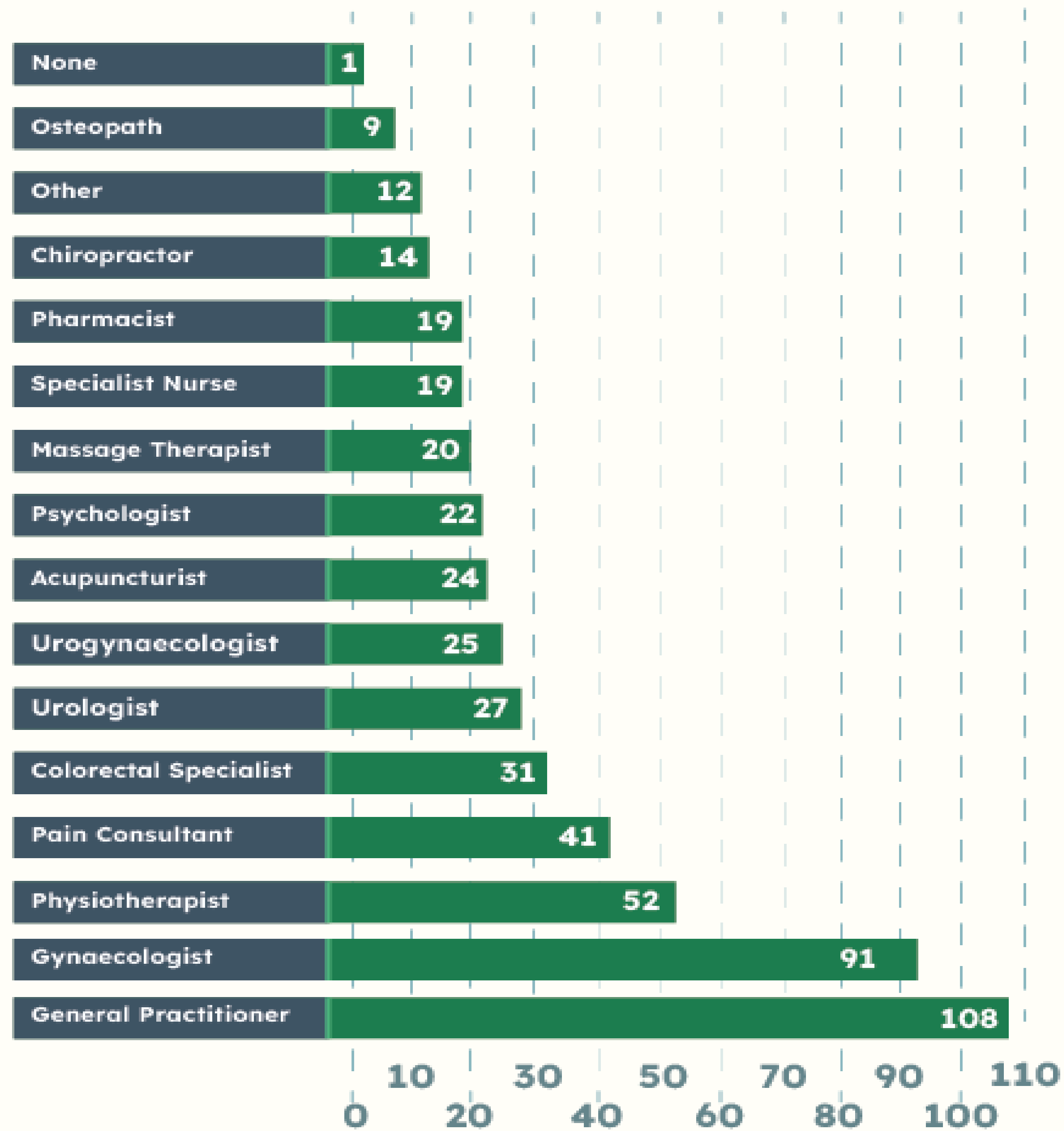

Which of the following medical professionals have you seen in relation to your chronic pelvic pain ?

" PAIN IS NOT MY JOB"

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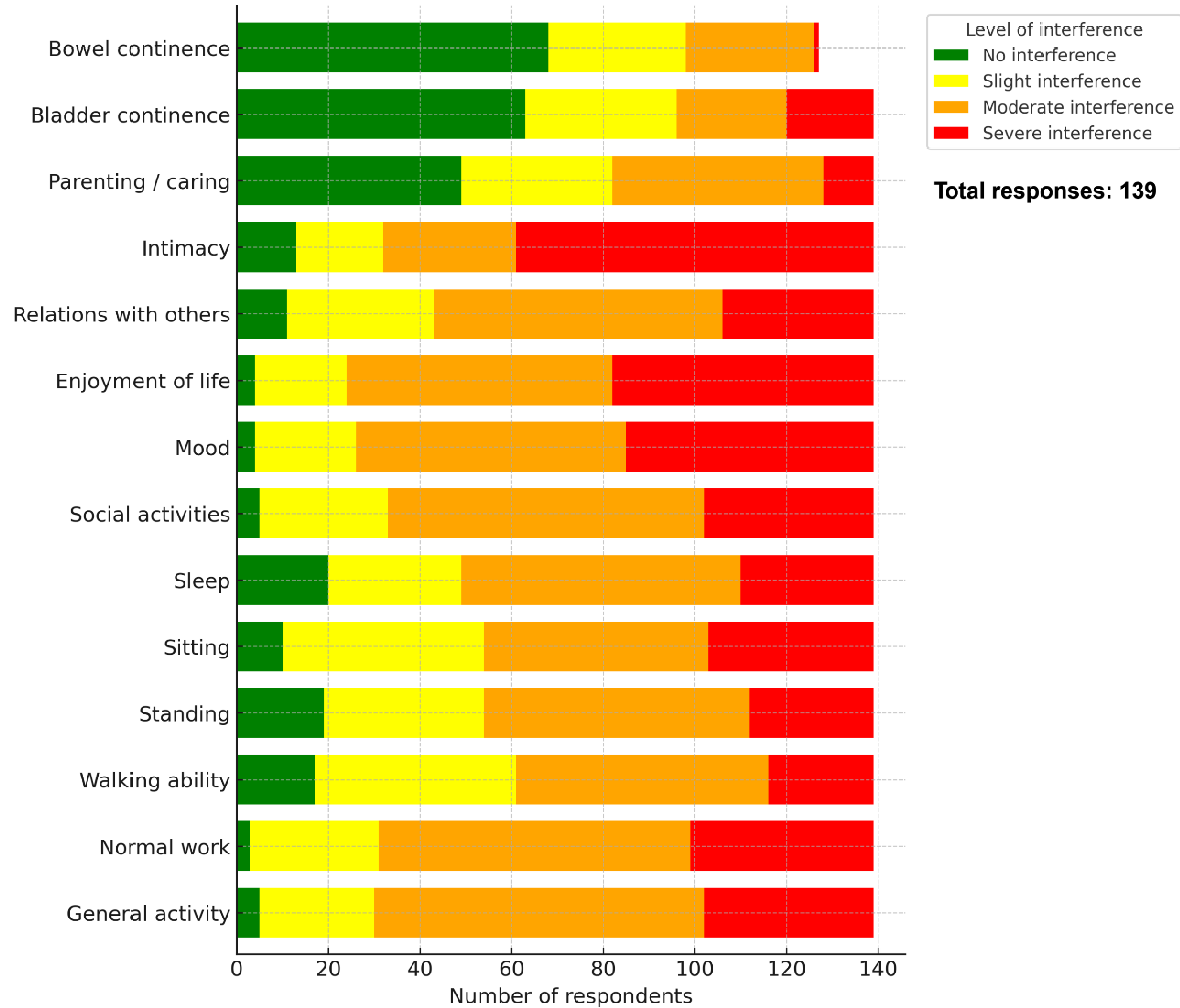
Extent of interference



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The impact of poor communication: Before, During, After imaging (1)

- Before imaging: checking information received about U/S examination
- Hygiene: explain
- Transducer for TVUS
- Verbal/non verbal communication
- What, how and when things were communicated to patients was not working !
- Poor communication between primary and secondary care professionals: different systems used: not compatible
- Specific options/choices pushed on patients rather than being discussed/had been missing at key moments in the process
- Communication unclear/confusing/issues with consent
- Anxiety compounded - leaving many desperately chasing professionals for updates or clarity

The impact of poor communication (2)

- Language can be harmful: professional response “ nothing of concern” when imaging doesn’t show a reason for the patients main symptom/concern

- Results arriving without context, leaving people alone to interpret medical jargon and manage fear. Results need **human context**

- Human capacities: Intuition, professional experience, empathy, relationship building

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Access to imaging

- Imaging advances in quality/availability for ovarian and deep endometriosis for surgical planning
- NCEPOD 2024 report "Endometriosis: A long and painful road" Just 9.6% of U/S scans performed by trained specialist
- Barely one in ten patients were discussed in an MDT meeting
- Lack of training contributing to delays in diagnosis
- 2024 International Consensus Statement on imaging of deep pelvic endometriosis and classification systems (Condous et al 2024)

Patients right to unbiased information for shared decision making

- Endometriosis: Increased emphasis on imaging
- Accurate, unbiased information needed: uncertainties, respect and validation of patient experiences and preferences Fang Q, 2024
- Patient understanding of imaging reports, disease location: ovarian endometrioma, visceral organs, ureters ,nerves required to enable genuine shared decision- making including presence/absence of adenomyosis/type
- Fallon L 2024 Healthcare Professional Perspectives: lack of time and perceived lack of knowledge
- Real world scenario, non-invasive tests, better quality studies, much potential for underestimated/underappreciated interventional approaches

Patient's values and preferences

- Are patient's preferences sought ?
- Not solely reproductive disorders, long term impact, pain, fertility, both
- Type and location of disease may impact patient's decision regarding treatment: surgery, conservative treatment
- Attitude to risk

How can AI assist ?

✓Can summarize , update patient summary in one place in understandable language: adjusted to an appropriate level that can be changed according to literacy

✓Patient needs to know who to go to if they don't understand, not left in limbo or having to be a detective !

✓Accountability and Reduce the burden for patients: Professional body chatbots to assist in finding relevant information in guidelines

✓General practice/Primary care/non-specialist settings

What is urgently needed ?

- Improved access to experienced sonographers/radiologists/interventional radiology
- Explanation/Understanding of findings
- Findings related to patient reported outcomes
- Improved information for patients to enable informed and shared decision making
- Patient preferences: not one size fits all
- Need involvement of imaging experts in this process at the beginning of the patient journey

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