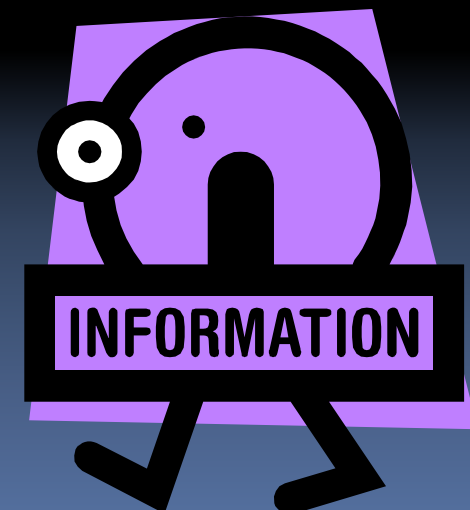
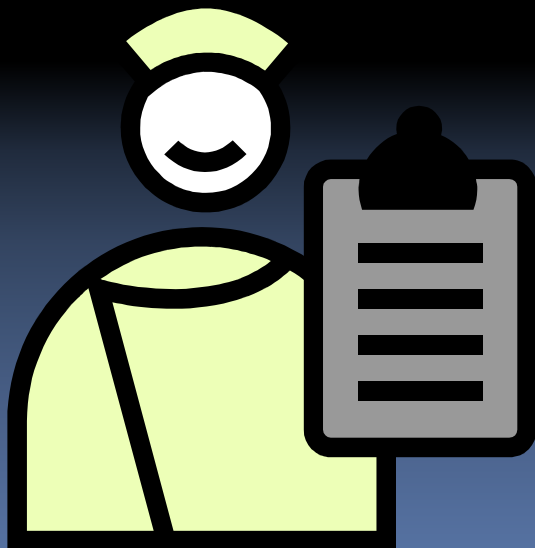


# INFORMATION PROVIDED TO PATIENTS WITH ADOLESCENT IDIOPATHIC SCOLIOSIS (AIS) AT THE FIRST POINT OF DIAGNOSIS IN THE HOSPITAL CLINIC: A SURVEY OF UK NHS SCOLIOSIS CONSULTANTS.

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## Background

- Seeking information is considered to be a process of sense-making whilst an individual is forming a personal point of view (Dervin, 1983).
- Uncertainty and anxiety are cited as being an integral part of this process, particularly at the initial stage of learning (Kuhlthau, 1991,).

- The Department of Health's, (DoH), Patients' Charter, states "every citizen has the right to a clear explanation of any proposed treatment including risks and alternatives before they agree to treatment (DoH, 1991 )."
- The role of the patient as an active partner in health care is now widely accepted and providing information to patients is considered fundamental.

Failure to fully address service users information requirements is consistently noted in the literature across different health conditions (MacCulloch *et al.*, 2009)

McCulloch (2009) investigated patient information needs before surgery but few studies are available that have addressed scoliosis patients information needs at the point of diagnosis

## Purpose

- The purpose of this survey was to determine the information needs of patients with AIS in the UK at the point of first diagnosis .
- What information sources/ materials are currently provided by NHS scoliosis centres?

# Materials and Methods

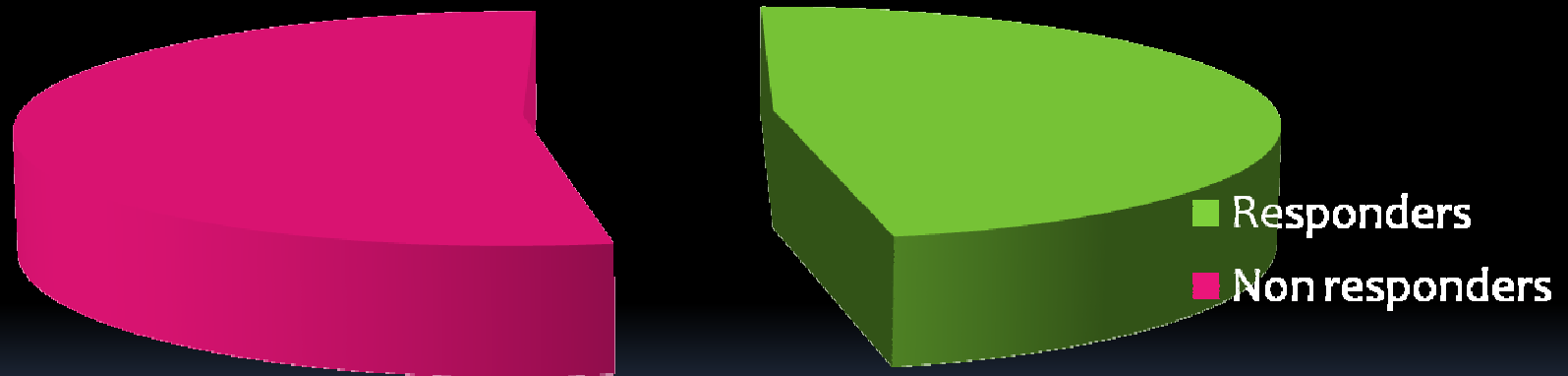
- An electronic survey was emailed to senior consultants at 30 key scoliosis centres in the UK



# Instrumentation

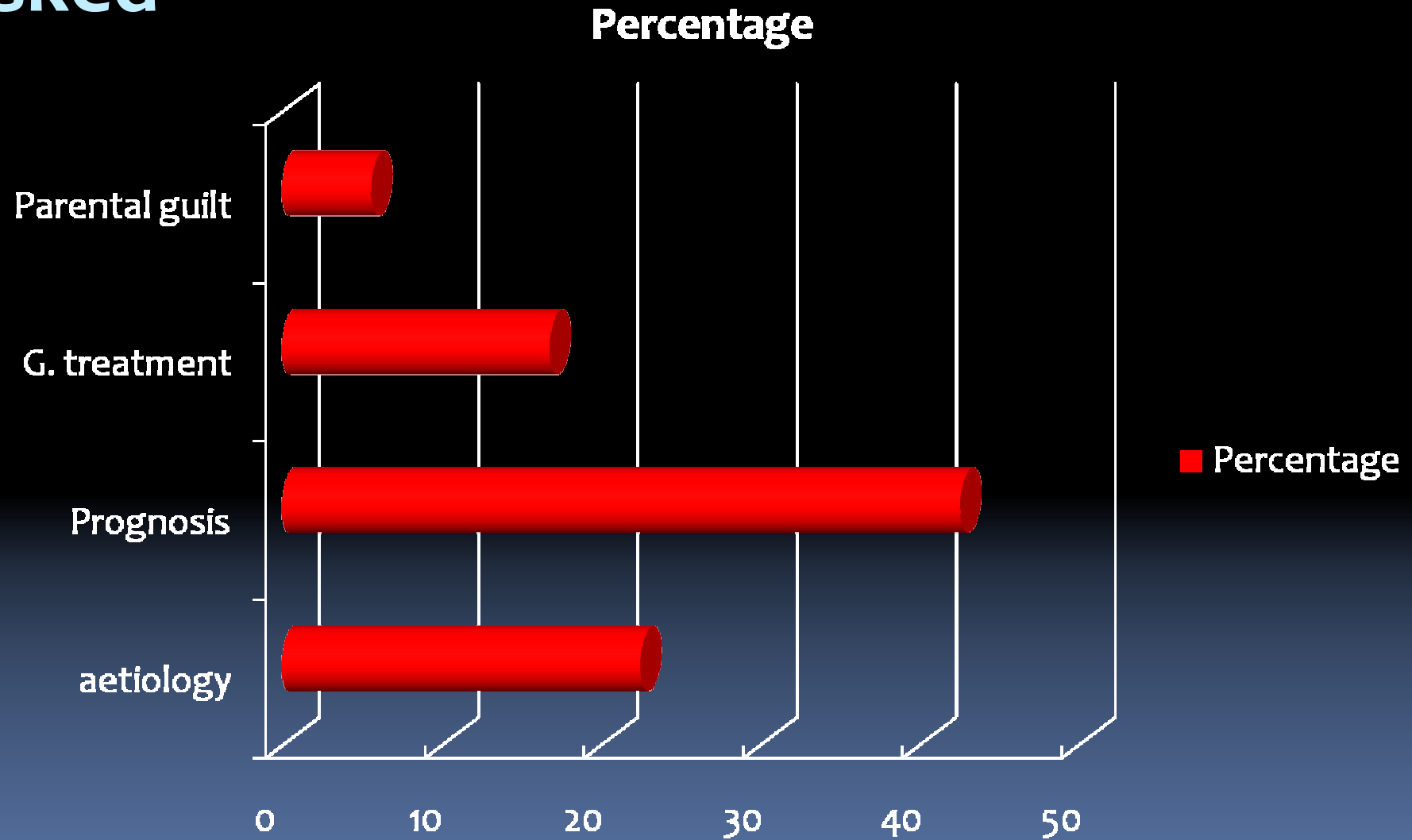
- The survey covered questions relating to:
- Most common questions asked by service users when first diagnosed,
- Whether any written information was provided
- Who had written this
- Whether patients were referred to any relevant web sites
- Any other concerns

Response rate 47%

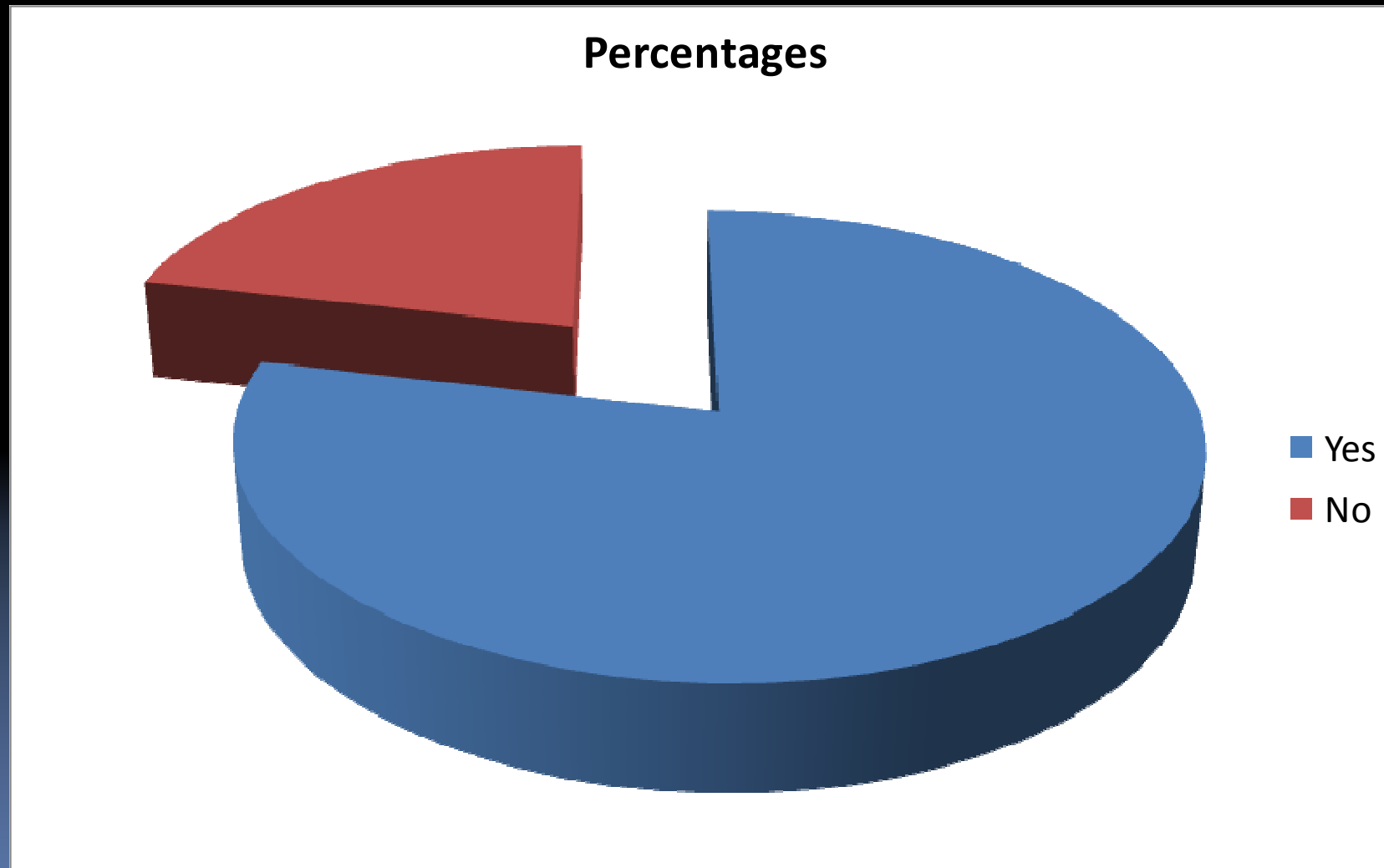




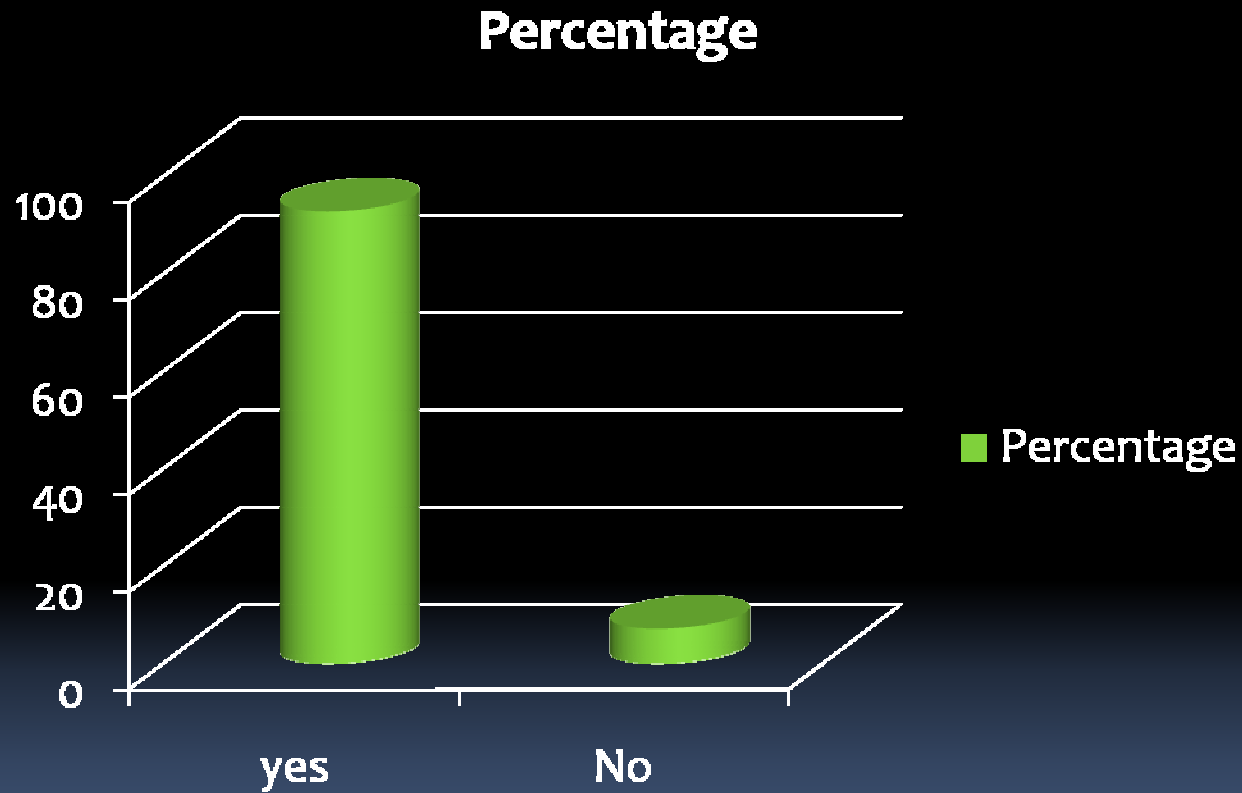
# Results : Most frequent questions asked



# Are Adolescents with IS and/or their parents given any written information?



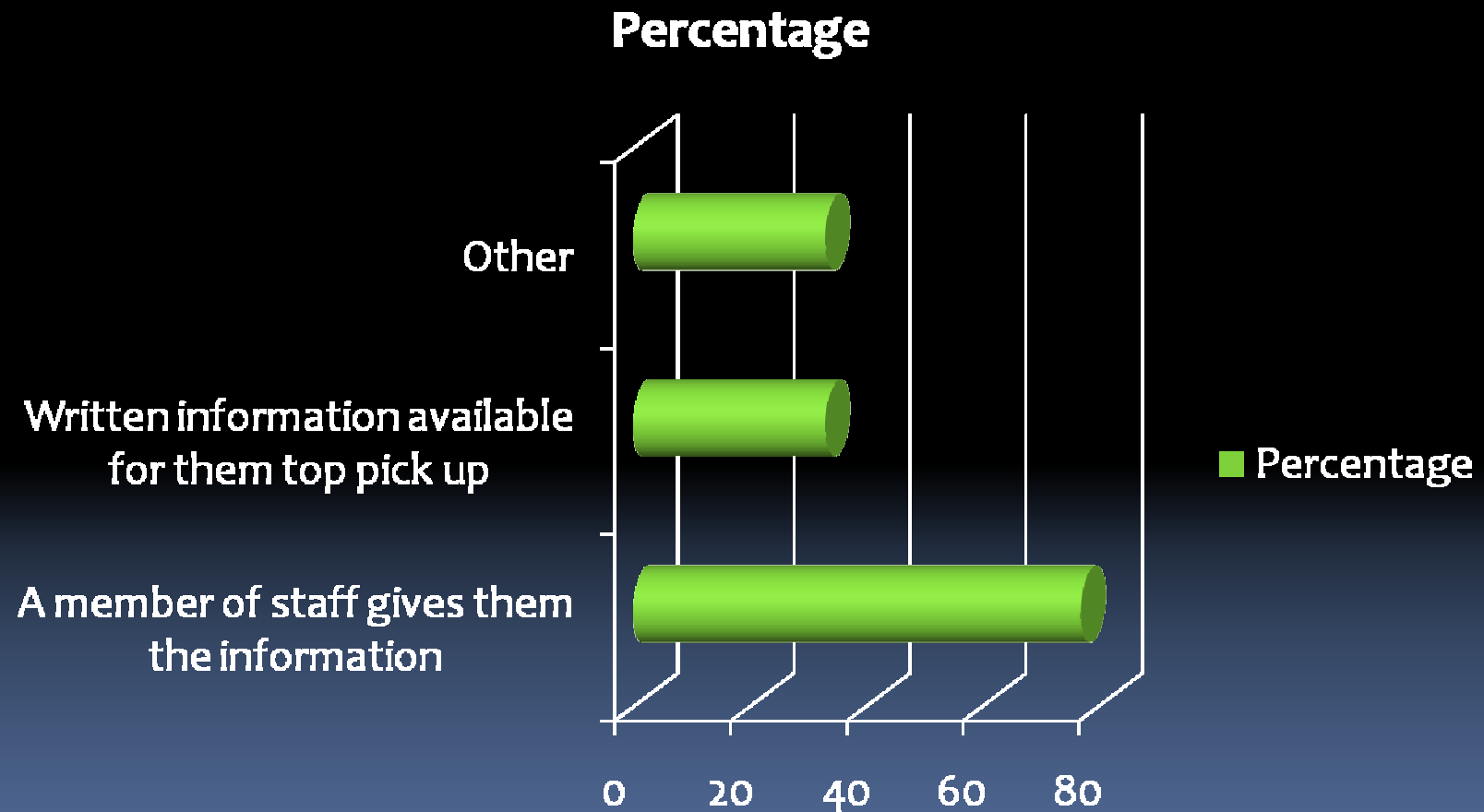
# Are patients referred to any web-sites?



# Websites Recommended by UK scoliosis surgeons

Website Name	Number of Recommendations
Scoliosis Association UK (SAUK)	11
Scoliosis Research Society (SRS)	10
British Scoliosis Society (BSS)	5
British Association of Spinal Surgeons (BASS)	3
Iscoliosis	2
Eurospine	1
Medikidz	1
British Scoliosis Research Foundation (BSRF)	1

# How do patients get hold of the information?



## Surgeons stressed importance for information to be:

- Evidence-based
- Address patients anxieties/counselling needs
- Provide clear natural history information
- Address ways of contacting other patients with AIS who have or have not undergone surgery.

# Discussion and Conclusions

- This survey suggests that patients are provided with information or referred to relevant web-sites in a significant number of scoliosis UK centres that responded.
- However it is still unclear whether or not web-sites address patients needs.
- Need to consider that results represent less than 50% of UK scoliosis centres



# Discussion and Conclusions

## Areas for further studies :

- The quality and content of information provided by NHS hospitals and at what point in the patient pathway it is provided.
- The actual quality and content of information on websites recommended by NHS scoliosis surgeons ie could it be making patients even more stressed and anxious?
- Service users perceptions of the quality and format of information currently provided by NHS scoliosis centres.





- Thank you for your attention
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