

A Good Clinic Appointment

Andrew Yeoman

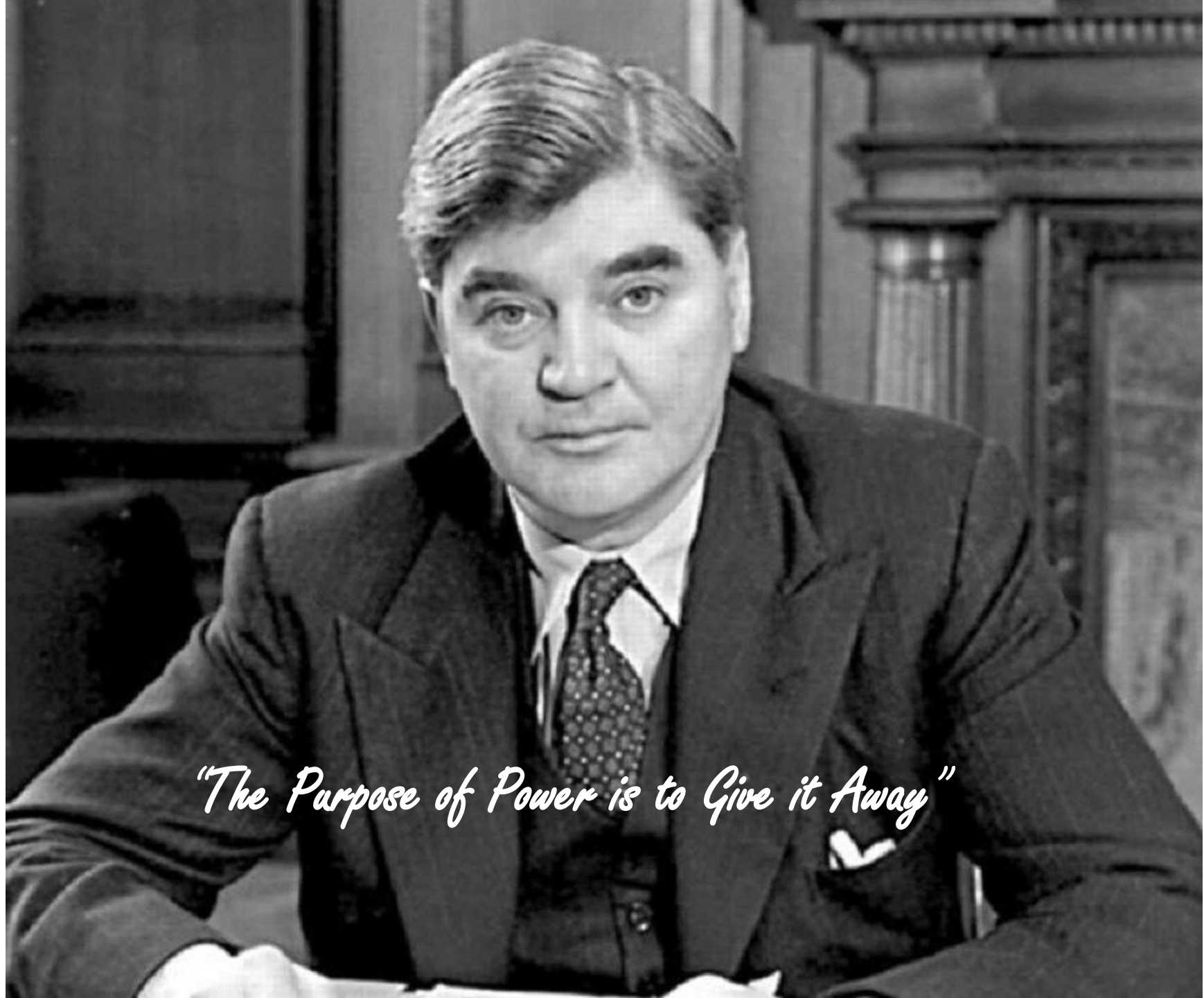
Hepatologist

Gwent Liver Unit

“
**Knowledge
is power.**
”

Francis Bacon

Buboquote.com



"The Purpose of Power is to Give it Away"

The Power Gradient in Healthcare

- Traditional healthcare model gave all the power to clinicians
- Patients reduced to a submissive or at best passive role
- This sometimes created an adversarial dynamic
- Significant progress has been made
but a long way still to go.....

Zero-Sum Game

My Interests
"I Win"

Your Interests
"You Lose"

We are opponents - when I win, you lose



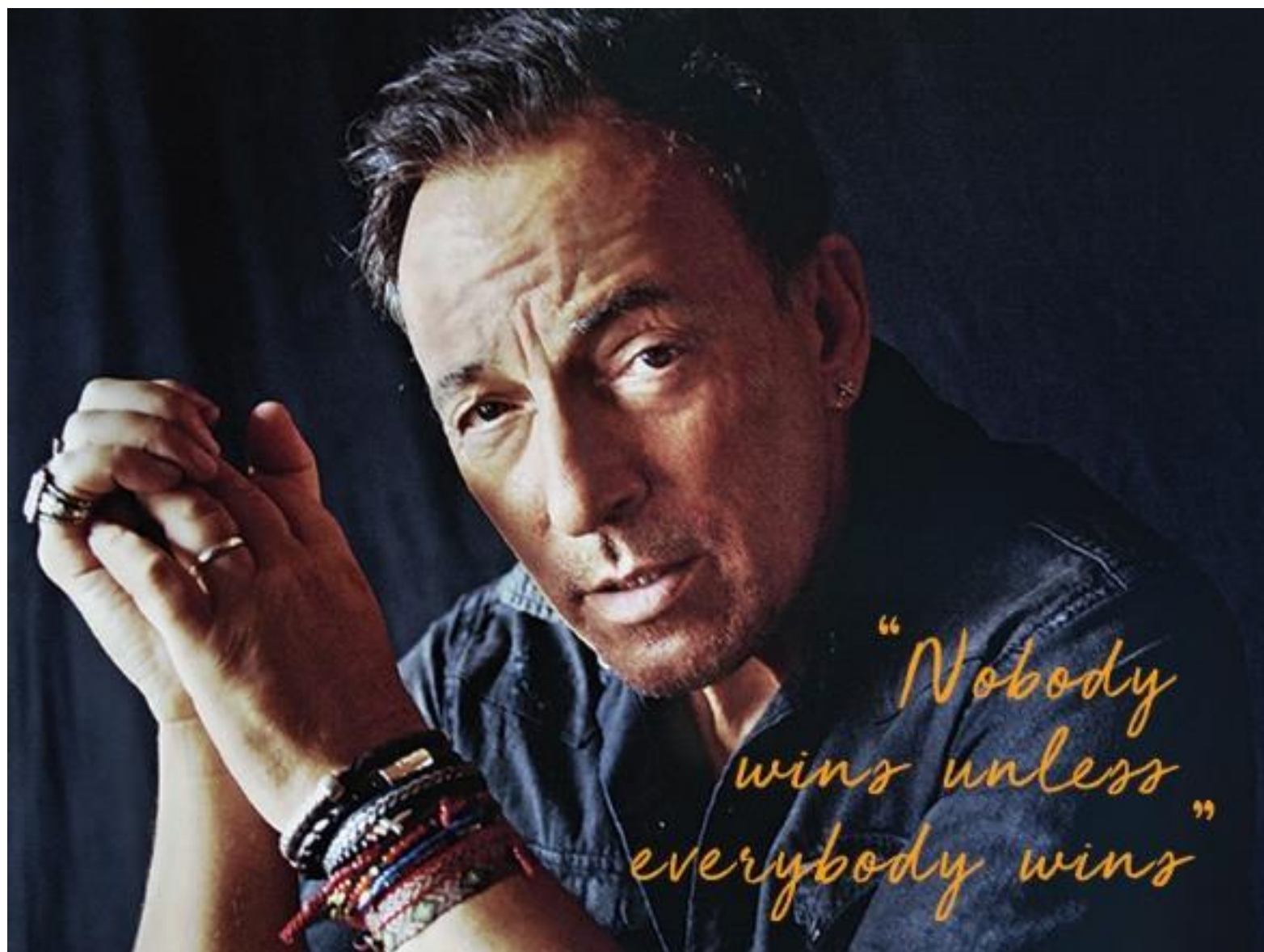
Non-Zero-Sum Game

My Interests
"I Win"

Area of
Overlapping
Interests
"Win-Win"

Your Interests
"You Lose"

We are partners – we win (or lose) together



*"Nobody
wins unless
everybody wins"*

Building effective clinician patient partnerships?

- Generic Definition:

“A partnership is an arrangement where parties, agree to cooperate to advance their mutual interests”

- A medical dictionary definition:

“**Health partnership** is commonly understood to mean the interactive relationship between a doctor and patient, the former advising on optimal strategies for improving or maintaining **health**, and the latter following the advice and taking charge of his or her own **health**”

Re-imagining partnerships in the 21st Century

UK General Medical Council: “The duties of a doctor” include to work in partnership with patients:

- Listen to, and respond to, their concerns and preferences.
- Give patients the information they want or need in a way they can understand.
- Respect patients' right to reach decisions with you about their treatment and care.
- Support patients in caring for themselves to improve and maintain their health.

Challenges to effective partnership working

- Health Care Professional
 - Time
 - HCP Knowledge & Experience
 - “Traditional” (paternalistic) mindset
 - Poor communication skills
- Patient
 - Previous bad experiences
 - May feel intimidated
 - Trivialise own symptoms
 - Excess faith in medicine and science
 - “There must be a solution”

Time Barriers To Successful Partnership

- Clinic slots are typically short
 - 20-30 mins for new patients appointments
 - 10-15 mins for follow up appointments
- Clinics often run late – adds to everyone's frustration
- Your condition is uncommon so you may have many questions that are previously unanswered

Knowledge Barriers to Successful Partnership

- Your doctor or nurse may not be that familiar with PSC
 - Rare disease
- Lack of Hepatologist's in UK
 - About half of hospitals don't have a hepatologist!
 - Many don't have a specialist nurse
- Still lots we don't know!
 - Science doesn't hold all the answers!

Paternalism impairs successful partnership

- “ I know best”
- Prevents a collaborative approach
- Fixation on medical endpoints of treatment may not tally with individual wishes
- Against the principle of “personalised medicine”

Communication barriers

- Time constraints can impair goal setting
- Clear communication on the above can help focus everyone on what matters most
 - For eg: “we have 20 minutes today, what would you like us to focus on”
- Signposting to trusted information resources can often fill in other gaps not covered & develops knowledge to “build on” in next consultation
- Conflict helps no-one in this setting
 - If you’ve had a previous difficult experience with a clinician and are seeing someone new, raise it but try and start with a “clean slate”

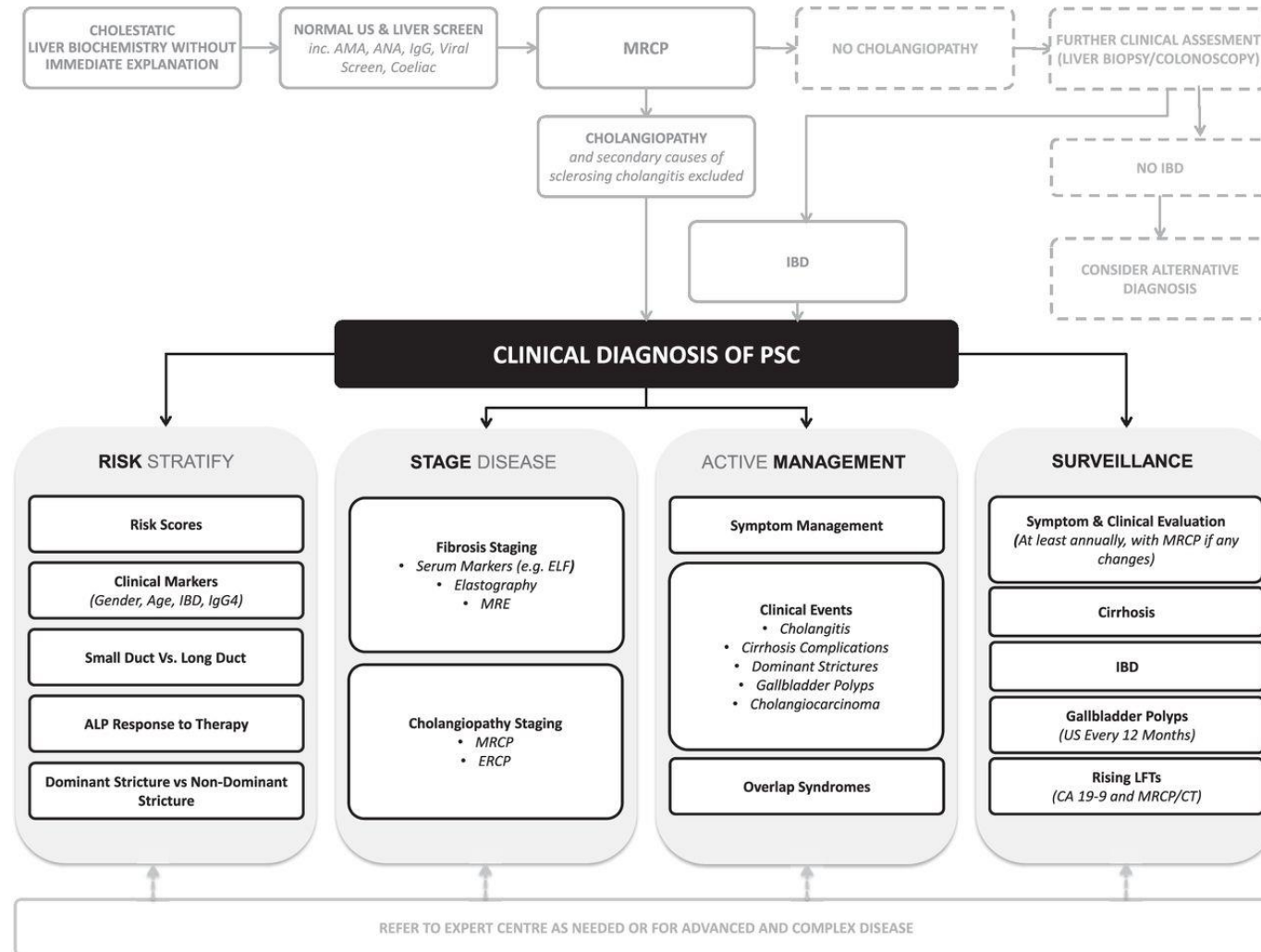
So what constitutes a good clinic appointment?

- Good clinical care
- Good communication
- Holistic needs are met

Important Information for your PSC Care

- Bile duct problems
 - Cholangitis
 - Jaundice
 - Pruritis (itching)
- Liver disease problems
 - Do you have cirrhosis?
 - Do you require cirrhosis monitoring (surveillance)
- Associated disease problems
 - IBD
 - Colorectal cancer risk
 - Bile duct cancer risk

Algorithm for the management of suspected primary sclerosing cholangitis.



Michael Huw Chapman et al. Gut 2019;68:1356-1378

Recommendation 4: We recommend risk stratification based on non-invasive assessment. Clinical scores are an emerging theme but no single method can be recommended at present to predict individual patient prognosis. Given the unpredictable disease course and the serious nature of the complications of PSC, patients should receive lifelong follow-up (*strength of recommendation: STRONG; quality of evidence: VERY LOW*)

Recommendation 8: We recommend that endoscopic screening for oesophageal varices should be done in line with international guidelines where there is evidence of cirrhosis and/or portal hypertension (*strength of recommendation: STRONG; quality of evidence: HIGH*).

Recommendation 9: We recommend that colitis should be sought in all patients with PSC using colonoscopy and colonic biopsies (*strength of recommendation: STRONG; quality of evidence: MODERATE*).

Recommendation 15: We suggest that provision of care should involve a partnership between patients, primary care and hospital-led specialty medicine with consideration made with regard to patient risk assessment, symptom burden and how local services are configured (*strength of recommendation: WEAK; quality of evidence: LOW*).

Recommendation 19: We recommend that all patients with PSC should have a risk assessment for osteoporosis. Once osteoporosis is detected, treatment and follow-up should be in accordance with national guidelines (*strength of recommendation: STRONG; quality of evidence: MODERATE*).

Recommendation 20: Poor nutrition and fat-soluble vitamin deficiency are relatively common in advanced PSC and we suggest that clinicians should have a low threshold for empirical replacement (*strength of recommendation: WEAK; quality of evidence: MODERATE*).

Recommendation 26: We suggest that an annual ultrasound scan of the gallbladder should be performed in patients with PSC. If polyps are identified, treatment should be directed by specialist HPB MDM (*strength of recommendation: WEAK; quality of evidence: LOW*).

Recommendation 27: We recommend that patients with PSC who have coexistent colonic IBD should have annual colonoscopic surveillance from the time of diagnosis of colitis in line with the BSG guidelines (*strength of recommendation: STRONG; quality of evidence: HIGH*). We suggest that those without IBD may benefit from less frequent 5-year colonoscopy or earlier in the advent of new symptoms (*strength of recommendation: WEAK; quality of evidence: VERY LOW*).

Recommendation 28: We suggest that in the presence of cirrhosis, HCC surveillance should be carried out in accordance with international guidelines (*strength of recommendation: WEAK; quality of evidence: LOW*).

Conclusions



Unwarranted variation in the care of PSC patients across the UK

- Risk stratification for liver disease
- Surveillance for biliary tract Cancer / gallbladder Cancer
- Exclusion of colitis at the time of PSC diagnosis
- Colonic cancer surveillance in patients with IBD-PSC



Patient-reported quality of care in primary sclerosing cholangitis

Martine Walmsley^{1,2}  | Dávid Tornai^{2,3}  | Nora Cazzagon^{2,4,5} | Angela Leburgue^{2,6} |
 Anna Mrzljak^{2,7,8} | Henrike Lenzen^{2,9}  | Marco Carbone^{2,10,11}  | João Madaleno^{2,12,13} |
 Ana Lleo^{2,14,15}  | Norman Junge^{2,16}  | Christoph Schramm^{2,17,18,19} |
 Annika Bergquist^{2,20,21} 

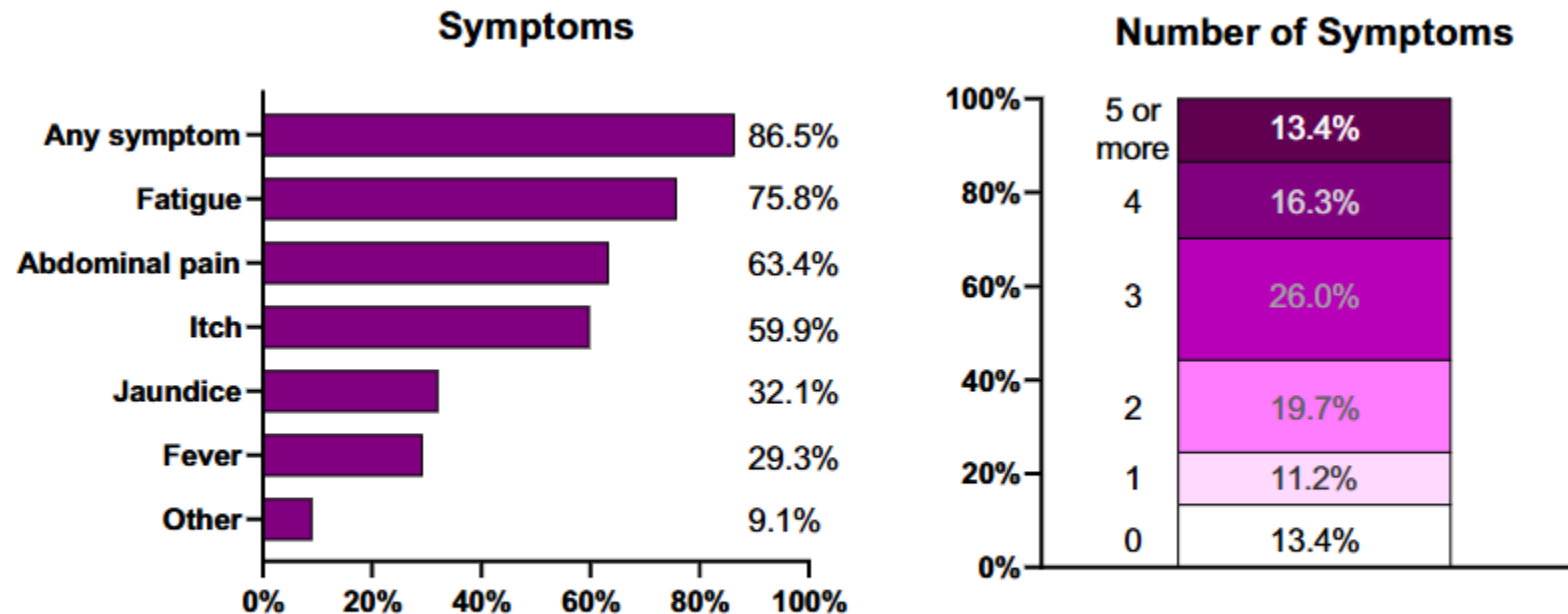
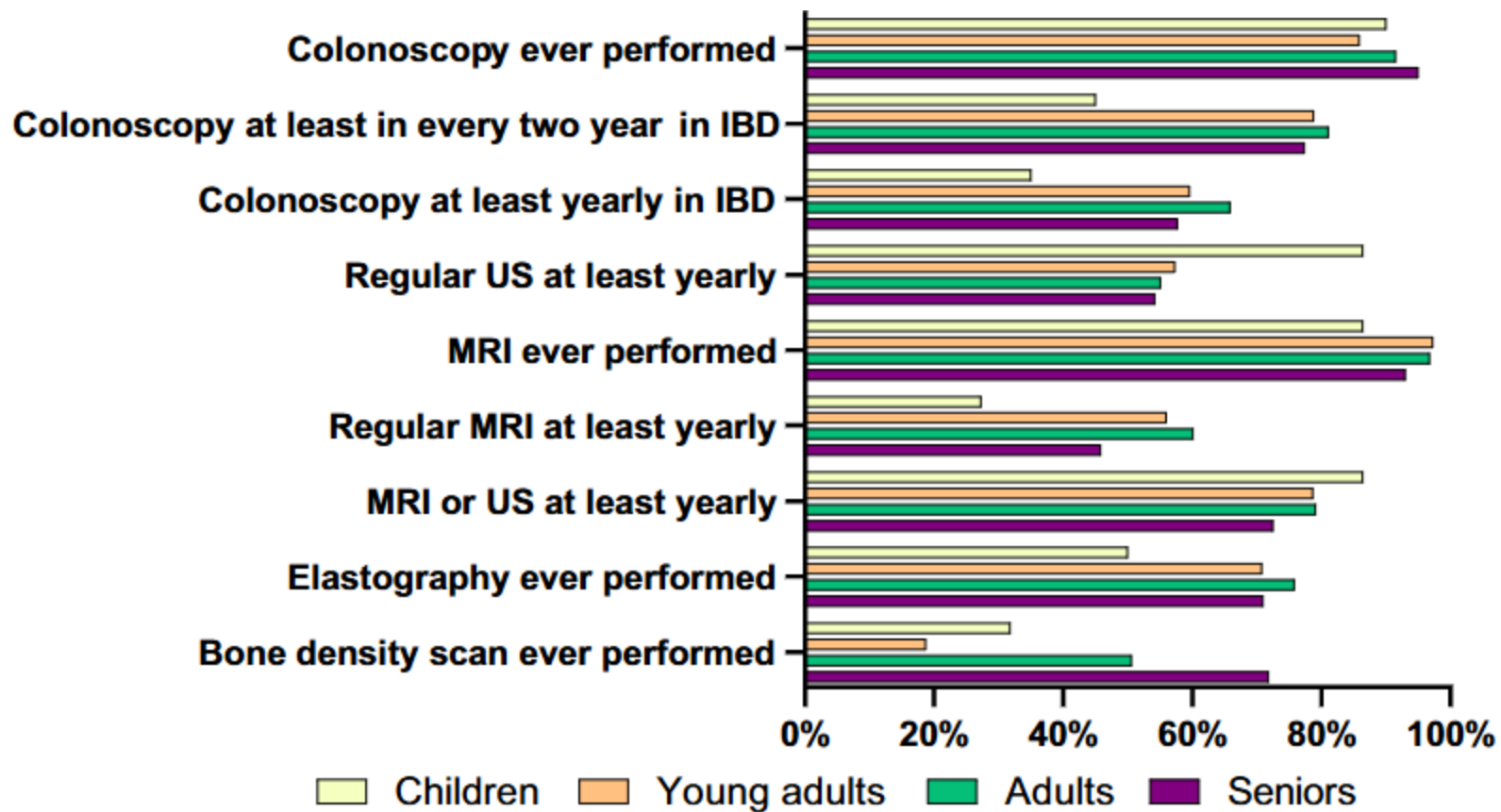


FIGURE 1 Symptom burden in 798 people with PSC.



Lets talk about Itch!

- Almost 2/rds of you will suffer with itch
- Extremely debilitating
- Should explore presence of major bile duct strictures with cholangitis and consider ERCP
- If not: medical therapy

TABLE 3 Medication for itch.

Medication	All (798)	In people with itch (478)
Any medication for itch	253 (31.7%)	237 (49.6%)
Antihistamine	143 (17.9%)	130 (27.2%)
Bezafibrate	33 (4.1%)	31 (6.5%)
Colestyramine	102 (12.8%)	99 (20.7%)
Naltrexone	15 (1.9%)	14 (2.9%)
Rifampicin	65 (8.1%)	62 (13.0%)
Sertraline	11 (1.4%)	11 (2.3%)

Top Tips: Getting the most out of your clinic appointment

- Be Prepared! Know about:
 - Your medical history inc all your current medication and doses
 - Your symptoms and timing of onset
 - Frequency, severity
 - What exacerbates or relieves them?
 - What troubles you the most about your PSC?
 - What do you want most out of a consultation?

What to know about your care provider?

- Which is your local hospital and nearest clinic
 - Know how to get there so you're not late
- Who is your caregiver (Consultant/specialist nurse)?
 - Make sure they provide their name – if not ask them!
- How do you contact them?
 - Do they have a patient advice line/email?
 - Don't be afraid to contact for further information
- You are entitled to ask for a second opinion!

Key PSC Related Questions: Liver scarring

- Do I have major liver scarring (cirrhosis)?
 - Most people don't have a liver biopsy so how has this been assessed?
 - Do I need a test for liver scarring?
- If I have cirrhosis: What do I need to look out for?
 - What monitoring tests do I need?
 - What symptoms should I report and to whom?

Key PSC Related Questions: Bile duct issues

- Especially if you have itch or episodes of cholangitis/jaundice
 - Do I have a bile duct narrowing?
 - If so how is this best managed?
- How do I manage my itch if I don't have a narrowing?
- When is my next surveillance ultrasound due?

Key PSC Questions: Associated conditions

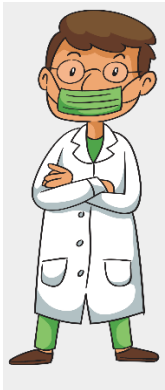
- If I haven't been diagnosed with IBD do I need a colonoscopy?
 - If I have IBD when is my next colonoscopy ?
- Do I need a bone density scan?
- Do I need to see a dietitian?
- Are there any local resources to help me manage my fatigue?

Who do I contact if problems arise?

Knowledge is power!

- The more knowledge we share the better we understand PSC and its effect on you
 - Doctors have in depth medical knowledge
 - YOU have in depth knowledge of the symptoms of your disease and how it affects YOUR life
 - Sometimes you will know more than some doctors as it's a rare disease
 - You are the expert in living with your condition
- Sharing your experience is powerful and educational to us
- Remember: The purpose of power is to give it away!

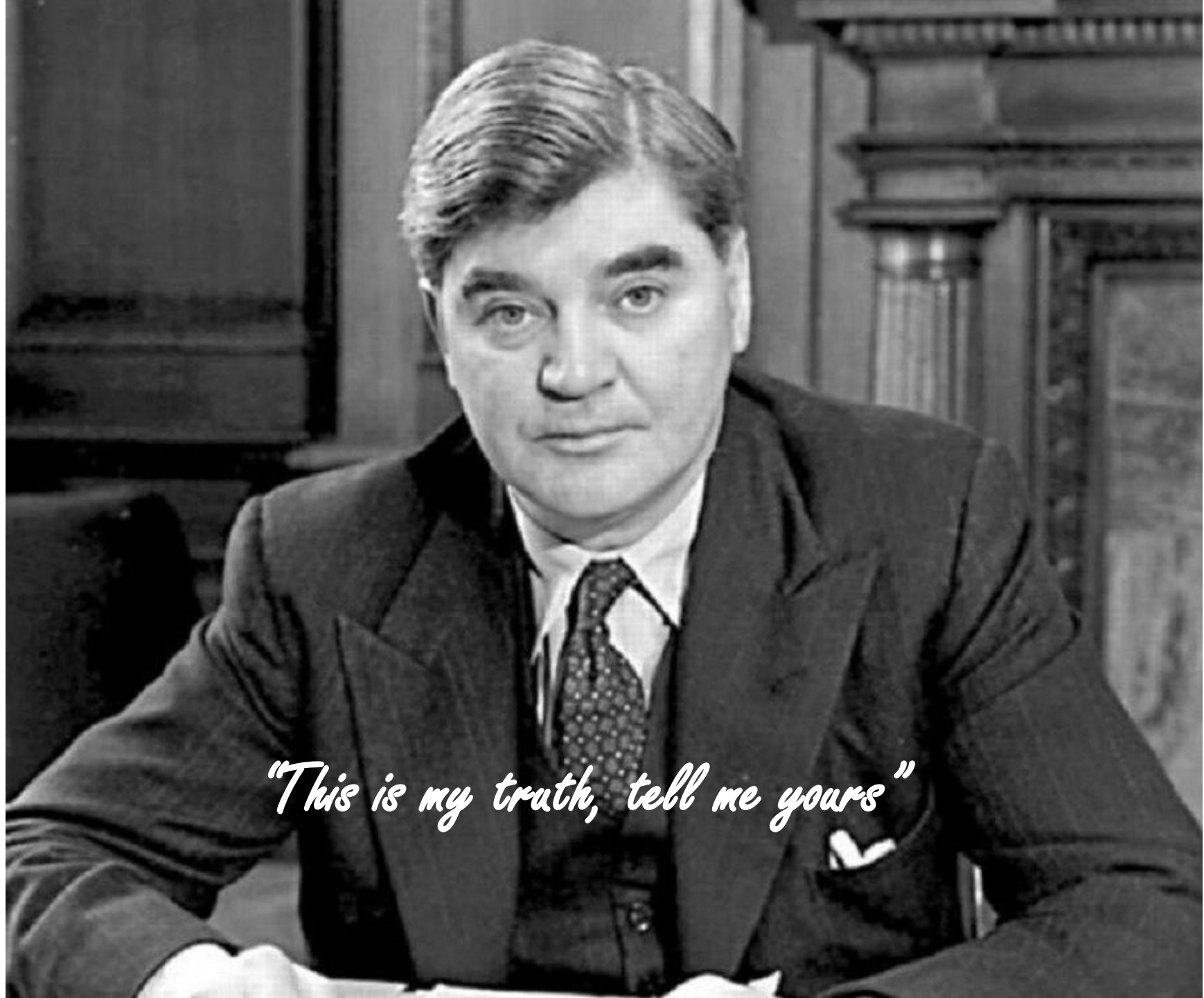
Moving beyond bipartite partnerships



you

Summary

- Developing partnerships are essential for high quality care in PSC
- Symptom burden, emotional wellbeing, medication compliance and long term outcomes can be affected by the success of a partnership
- Developing mutual trust and respect are integral to this, is extremely rewarding for all parties and facilitates a good appointment
- PSC Support has a crucial bridging role in fostering partnerships by providing essential support and information provision



"This is my truth, tell me yours"