

Minute of PPG Meeting 12th January 2026 – Extracted from Recorded Notes

Attendees: Sarah Setterfield, Elspeth Woods, Jane Hanlon, Gordon and Angela Lovell, Bob and Vanda Gould, Bruce Battams, Steve Bates, Liz Mold, Anne Minihan, Mary Tait, Fay Read

Apologies: Shona Manson, Clive Robinson, Christine Cartwright, Judith Westell, Jan Lloyd, Jacqui Coleman, John Neale, David Vaughan, Sandra Whitefoot, Sheila Dale, Mark Pitman, Tania Pal

1. Raising Awareness and Support: Insights from the Milton Keynes Prostate Cancer Support Group Meeting (Malcolm Carpenter)

- Milton Keynes Prostate Cancer Support (MKPCS) is a volunteer group founded in 2014 to help men diagnosed with prostate cancer and to raise awareness of early detection.
- They partner with Prostate Cancer UK, Tackle, Milton Keynes Cancer Forum and local hospital teams—all funded by donations, no paid staff.
- Prostate cancer is now England's most diagnosed cancer (56,000+ cases/year), but no national screening exists. Early PSA testing, MRI scans and targeted biopsies improve outcomes.
- Risk factors include age (50+), family history, being Black, and rising PSA levels from cycling, sex or infection can trigger follow-up tests.
- Treatments range from surgery and radiotherapy to hormone therapy, HIFU or active surveillance depending on cancer stage and patient age/health.
- MKPCS offers monthly peer-support meetings, telephone help, literature, outreach events and quarterly private PSA testing.
- The PPG meeting wrapped up by discussing operational items—new tablecloth, setting up a WhatsApp group, and planning future agendas around community engagement and wellbeing events.

Presentation bullet points

Who we are (Milton Keynes Prostate Cancer Support)

- Founded in 2014 at urologists' request—filled the gap in post-diagnosis support for men and families
- Entirely volunteer-run, charity status but no paid staff, reliant on donations
- Big Yellow Box Milton Keynes provides free storage for group materials
- Partners with Prostate Cancer UK, Tackle (national support network), Milton Keynes Cancer Forum, Macmillan nursing staff and neurology teams

Mission and goals

- Provide peer support for anyone affected by prostate cancer (patients, partners, families)

- Increase public awareness of prostate cancer and benefits of early detection
- Offer information, literature, signposting and personal experience sharing
- Run private PSA testing for those who cannot access GP tests

Prostate basics

- Walnut-sized gland under bladder that surrounds the urethra
- Produces semen to carry sperm
- Only men have a prostate (some women ask!)

Key prostate cancer facts

- Most commonly diagnosed cancer in England (56,000 cases yearly), surpassing breast cancer
- ~12,200 men die from prostate cancer each year in UK
- No national screening program—men must request PSA tests from GPs or private providers

Diagnosis and screening pathway

- PSA blood test measures prostate-specific antigen level in bloodstream
- Elevated PSA may result from cycling, sexual activity, infection or cancer
- If PSA abnormal: repeat PSA, then MRI scan (non-invasive)
- Targeted biopsy only if MRI suggests possible cancer—more precise than older random biopsies
- No national one-stop screening like breast cancer; local hospitals aim to streamline but capacity limits exist

Risk factors

- Age: most common after 50; screening advised from 45 (especially high risk)
- Family history: father or brother with prostate cancer = 2.5× higher risk
- Maternal relatives with breast/ovarian cancer also raises risk
- Black men: up to 1 in 4 lifetime risk vs 1 in 8 for other UK men; reasons unknown

Symptoms (often absent until advanced)

- Difficulty urinating, blood in urine/semen, pain in back/hips/ribs, leg swelling or fatigue
- By symptom onset disease often well advanced
- Many treatment side effects mimic these symptoms

Treatments (depend on stage, aggressiveness, age, health)

- Radiotherapy (electron beams: external beam or brachytherapy seeds)

Radical prostatectomy surgery (prostate removal)

- Hormone therapy (lowers testosterone; menopause-like side effects but effective)
- High-intensity focused ultrasound (HIFU)—non-NHS locally, single-session prostate ablation
- Active surveillance (“watchful waiting”)—regular PSA monitoring and action on rising trend

Personal experiences

- Sir Chris Hoy diagnosed at 41 after shoulder pain turned out to be bone metastases from prostate cancer
- Member given three months to live in early 2000s—radiotherapy gave him 18 more years
- Local members share Gleason scores (e.g. 3+3 → 3+4) guiding treatment choices

How MKPCS supports patients and families

- Monthly face-to-face meet-ups (30+ attendees) for chat, presentations or informal support
- Quarterly private PSA testing events (£25/test covers phlebotomist, lab work, results emailed in 48 hrs)
- Telephone helpline manned by committee members with lived experience
- Free literature, website resources, leaflets and invitations to community events
- Regular outreach at companies and health forums to deliver presentations

Private PSA testing details

- Hosted four times a year on Sunday mornings, in local venues
- Cost £25 (no markup)—covers booking, phlebotomist, lab analysis and emailed results
- Promoted to men unable to get GP tests or fit appointments into work

Sarah thanked Malcolm and David for an informative presentation and for their honesty and openness about their own experience. The PPG gave a voucher as a token of our appreciation.

2. **PPG meeting operational items**

- ✓ Funding a new tablecloth—practice happy to supply quote, PPG agreed to cover cost
- ✓ Proposed a PPG WhatsApp group rather than use the email address. This will give real-time coordination for events such as vaccination clinics, meeting reminders). This was agreed and phone list to be collected
- ✓ Agenda structure—focus each month on a theme rather than broad AOB;
- ✓ A clear monthly PPG agenda theme, plus real-time WhatsApp group coordination, will boost productivity, event planning and volunteer engagement.

- ✓ Small, targeted community events (e.g. talks, singing group) in local venues can raise practice visibility and patient participation. Singing group (led by PPG member) seen as strong wellbeing activity—could expand invitations
- PPG outreach ideas—use local halls or church rooms for patient education events, invite speakers on targeted health topics, partner with nearby practices or neighbourhoods

Actions for next meeting

- a. February's theme: promoting health & wellbeing + community engagement—everyone to think of 3 concrete ideas in advance
- b. Minutes to be issued within a week to allow follow-up actions well before next meeting
- c. Collect mobile numbers at next meeting for WhatsApp setup. Please email RedHouse email with your mobile number if you haven't already given Elspeth your phone number.

Meeting closed at 20.10.

Next meeting Monday 9th February 2026 6pm for 6.30pm start.

Guest speaker Lucy Jones – Alzheimer's Society