All Party Group on Cancer hears from practitioners and patients

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Summary
The All Party Group on Cancer has heard from practitioners and patients on cancer services

Witnesses included:

First set -
Professor Ann Barrett, Dean, Faculty of Clinical Oncology, Royal College of Radiologists
Charlotte Beardmore, Society of Radiographers
Dr Clair du Boulay, Vice-President of the Royal College of Pathologists
Professor Jonathan Waxman, Professor of Oncology

Second set -
Dame Gill Oliver, Director of Service Development, Macmillan Cancer Relief
Joanne Rule, Chief Executive, CancerBACUP
Michael Scanes, Carer
Jenny Walton, Patient

The first set of witnesses represented the world of medicine. They were supportive of the government's commitment to cancer services, but highly critical of the PCT structure, urging a regional and national overarching strategy. They also highlighted the overwork and stress suffered by health professionals, leading to burn out.

Ian Gibson MP, who chairs the all-party group, asked if the PCT were following the government in setting cancer as a priority. Professor Ann Barrett told the meeting that this was recognised as a priority, due to government policy, but that cancer is not seen as a major problem in day-to-day activity. PCTs see different priorities to the government at a local level, she explained.

Professor Jonathan Waxman added that PCTs have huge agendas, and do not have the specialist knowledge for such a broad spectrum of cancers. Dr Clair du Boulay agreed that there was little understanding of the costs of having specialist knowledge underpinning PCT work.

Ian Gibson then asked if cancer was different to other services, and Charlotte Beardmore stated that it was very diverse, covering a wide range of different treatments. Claire added that targets on pathology had opened the lid of a Pandora's box, showing the lack of capacity in the sector.

Jonathan Waxman criticised the balance between autonomy and centralisation, which he described as 'completely awry'. The government is willing to improve cancer services, he stressed, but the market forces in the NHS are damaging this at PCT levels.

Baroness Finlay then asked if commissioning should be changed, with collaborative groups to work between SHAs and PCTs. Jonathan Waxman welcomed this suggestion, stressing that while the current arrangements were based on sound principles, they were more for arranging hip surgery or care rather than special cancer treatment.
Ann Barrett stated the NSFs for other illnesses were good, but that PCTs were not good. Central planning is needed, she continued, and while extra funding is welcome, PCTs have to take decisions about bigger investments, leading to investment stopping.

Baroness Finlay asked if cancer was about to move down the political agenda when targets are reached. Ann Barrett welcomed the use of targets, stating that they stimulated partnership working and a focus on improvement. She attacked the use of penalties however, calling for rewards instead. Charlotte Beardmore agreed, stating that targets had highlighted a lack of staff. She also agreed that the PCT structure made getting funding difficult and time consuming, noting a case where a hospital had been bought equipment but could not get funding for a bunker to house it.

Ann Barrett went on to criticise the 'enormous bureaucracy' involved in cancer services, particularly in cancer networks. She criticised the number of attendees to the meetings of the networks, calling for the SHA to instead take in the lead in developing regional strategies.
Baroness Finlay asked witnesses to send later a summary of the hours and staff involved in this.
Clair du Boulay suggested that there be a coordinator in every region, with an overall strategy offering the same footprint for NSFs, PCTs, and SHAs.

Jonathan Waxman attacked the large number of administrators in the NHS, claiming that there were the same number as of nurses. Asked for examples of the worst experiences in this, Ann Barrett replied that the short-term approach of commissioners was frustrating. The ten year rolling plan to replace equipment is not taken on board, she stated, repeating the example of equipment which has not bunker.

Jonathan Waxman criticised the waiting time levels, and Charlotte Beardmore agreed, noting that any equipment difficulties held back work. In her area, private money had been used to cut waiting times, she continued, describing this as 'terrible' as this should be put towards increasing service.

Clair du Boulay pointed to difficulties in training new pathologists due to heavy workloads. Although funding had provided for extra posts, these had not been enough. There are at present 200 vacancies without applicants, she stressed, due in part to early retirement. Demoralisation is the key problem, she concluded.

Charlotte Beardmore suggested a change in working methods, with funding for new roles. The high level of female workers means that maternity leave has to be provided for, she told the meeting, and HR are too rigid to offer flexible working, childcare and part-time posts. Lincoln had a good model to be followed, where a nurse consultant has been set up, allowing hands on work to be combined with consultancy, she added. This offers an alternative to the management route, and could be set up in other staff groups too. Therapeutic staff have a vast amount of expertise which is not being used, she concluded. Charlotte Beardmore promised to send the group figures on the number of women lost to the profession, agreeing that many would return with childcare, flexible working and golden hellos. Other witnesses supported this suggestion, stating that it should be organised at a national level across professions.

Jonathan Waxman warned of the effect of increased student fees on attracting graduates to the profession. He noted that his third year students were already £30,000 in debt, with 70 to 80 per cent of them having to work as waitresses or bar staff as well as their studies. This 'can't be right' he argued, particularly since the starting salary is £16,000 for a radiographer - the same amount as the tuition costs.

Ann Barrett complained about the devaluation of expert opinions in current culture, stating that in the existing bureaucracy all opinions are counted as equally valid. This leads to demoralisation, she warned. She blamed problems in recruitment and retention of poor management, a lack of investment in the infrastructure and a 'morass of inefficiency'.

On retention, Charlotte Beardmore told the committee that health staff wanted to care for patients, and that the stress and workloads they are experiencing means that they can't offer the best service.

Discussion continued on targets and bureaucracy, and Clair du Boulay offered an example of unnecessary bureaucracy. She told the meeting that the CNST requires documentation to prove that all junior doctors are competent. By definition, junior doctors are in training, she explained, and under supervision. In any case, it would be impossible to certify a doctor as competent all the time, as everyone is likely to make mistakes at some point.

I.T. was another problem highlighted by witnesses, with differences in systems requiring replicated data entry.

Ian Gibson concluded by asking witnesses what they would most like to say to Health Secretary John Reid. Ann Barrett called for a central strategy with expert input. Jonathan Waxman offered praise for the government's commitment to cancer work, but called for centralisation to offer guidance to PCTs, which are 'clearly not working'. Charlotte Beardmore also praised the government, recommending a strategic look at purchasing huge prices of equipment at a regional or national level. Clair du Boulay offered her welcome for increased funding for training, but reiterated that PCTs do not have the vision or the werewithal to develop strategies.

The second set of witnesses represented patients. They praised the secondary care they received in general, but called for better information for patients. The increasing involvement of patients in health policy was welcomed.

Ian Gibson MP asked if cancer was a priority for GPs. Jenny Walton, who was diagnosed with vulva cancer, stated that this was important for her GP. Roger Wilson, who had sarcoma and set up Sarcoma UK, stated that while GPs did care about cancer they lacked the skills to diagnose

cancer, passing on diagnosis to others.

Michael Scanes, who cares for a wife with ovarian cancer, noted that his wife had not been diagnosed for a year, as her symptoms were not taken seriously due to the fact that she continued working. However, her treatment since diagnosis has been 'absolutely fantastic', he stressed. Michael Scanes saw a role for GP specialists.

Joanne Rule of CancerBACUP agreed, noting the difficulty in reaching GPs, and stating that cancer detection could not be a priority for them as experience is needed.

Gill Oliver, of Macmillan Cancer Relief, concurred, adding that the new GP contract did not offer many points for cancer. The PCTs should listen to the local population when deciding priorities, she argued.

Ian Gibson then asked about the cancer networks, which had been criticised by earlier witnesses. Witnesses were enthusiastic about these, with Joanne Rule stating that they had engaged with patients and delivered change. They are led by cancer clinicians and patients, and they work, she concluded, offering the 'fresh air of pragmatism'.

Gill Oliver added that the networks offer a focus for cancer knowledge and information, promoting awareness of cancer patients' needs.

Witnesses concurred however with earlier criticism of PCTs, stating that commissioning often seemed disjointed.

Jenny Walton offered her own experience of the health system, noting that it had taken a year before she was referred to a gynaecologist, and that she had gone private to have a hysterectomy, then a partial vulvectomy and then a vulvectomy. She since returned to the NHS due to high costs, but her gyn oncologist has left, and there are no applicants to fill their vacancy. She remains slightly unsatisfied with the competence of her current gynocologist. Jenny Walton called for more information to be given to patients on the physical and mental effects of a vulvectomy. In her case, support had been offered only when she suffered a panic attack in hospital. Jenny Walton was keen to stress that there was now more support for patients.

On patient involvement, she stated that the cancer network is on a steep learning curve, she added. She praised the fact that medical staff were listening to patients however, noting that when she helped with training, staff offered their thanks to her. Jenny Walton also called for more female staff to deal with such cancer and to have the same doctor.

Gill Oliver called for such experiences to be listened to, and used to develop guidance and consistent standards which can be understood by all.

On targets, Joanne Rule warned against 'throwing out the baby with the bathwater', stating that some cancer targets, such as the 2 month waiting list had been of great value. She called for central coordination and strategic thinking of the effects of targets on each other however.

Gill Oliver repeated earlier points about the burn-out of NHS staff, calling for a 'radical' look at the professions and work division. Jenny Walton pointed to an initiative where lead nurses are holding follow up clinics as a good example.

Finally, on funding, Joanne Rule called for ring fencing of funding. Gill Oliver added that there had been a heavy tracking exercise with recent NHS funding, with pressure ensuring that the money is spent as intended.

Ian Gibson closed the session by asking the witnesses what they would most like to say to John Reid.

Roger Wilson called for quick and accurate diagnosis, and Jenny Walton drew attention to the 'atrocious' food in hospitals. Gill Oliver urged consistent and common standards that everyone can understand, with patients being involved in monitoring resources. Joanne Rule warned that devolving commissioning to 300 PCTs was not possible.