

Supplementary Material

We merged the data obtained from the two consultations in England and Germany to combine all information about contextual enablers and barriers in one country. If participants explicitly mentioned that certain information applies to home-based palliative care in contrast to reinforced HBPC this is mentioned in the summaries.

Table 1 Expert consultation findings in England

| Domains | Identified barriers | Suggested solutions |
|-----------------|--|---|
| Geographical | <ul style="list-style-type: none"> • Difficult access in rural areas • Resource implications to guarantee access (see Funding) • Heterogeneity of HBPC service throughout England | |
| Locational | <ul style="list-style-type: none"> • Sometimes housing not appropriate (heating, cleanliness, lighting etc.) • In the beginning HBPC can be felt as an intrusion | <ul style="list-style-type: none"> • Usually staff can manage due to existing referral routine within palliative care: questions on form to ensure everything is prepared (risks in house, facilities, medication) |
| Epidemiological | <ul style="list-style-type: none"> • For the very old, HBPC can be difficult (housing situation, basic care) and an informal caregiver is essential for very old patients • Very old people have reduced access to palliative care services • Fast disease progress can be hard on patients and family | |
| Socio-cultural | <ul style="list-style-type: none"> • Cultural mix in England that rHBPC should recognize • Disagreement with HBPC by family member • Disagreement with treatment by family member • Psychological defence mechanisms of family leading to problems (families collude in trying to save patient's feelings) • Patient's defence mechanisms (e.g. refusal of equipment at home leading to medical problems when needed urgently) • Language barriers | <ul style="list-style-type: none"> • Needed provider skills: cultural sensitivity, communication skills, cultural treatment skills • Information in different languages • Available professional translator, however, often a family |

| Domains | Identified barriers | Suggested solutions |
|----------------|--|---|
| | | member can translate |
| Socio-economic | <ul style="list-style-type: none"> Poverty is a major factor for inadequate access to palliative care HBPC is available to all social classes (in contrast to hospice = middle class) Different view of death and dying among different socio-economic classes (tied to geographical areas, e.g. miner region) Housing issues related to poverty (heating, cleanliness) which makes HBPC difficult For working family members HBPC can be restraining due to lack of time/resources | <ul style="list-style-type: none"> Existing referral routine within palliative care: questions on form to ensure everything is prepared (risks in house, facilities, medication) Respite care (“variable intensity palliative care”) available in some institutions to offer family members time to go shopping etc. (in final few weeks) |
| Political | <ul style="list-style-type: none"> Governmental priority influences HBPC implementation, financing etc.: at the moment it is high priority but this can soon change due to a change in government Changing priorities depending on the government in charge (legislation period) | |
| Legal | <ul style="list-style-type: none"> Situation can be difficult for informal caregiver | <ul style="list-style-type: none"> Legal protection for informal caregiver |
| Ethical | <ul style="list-style-type: none"> Preferred place of death should be acknowledged, bed-availability in hospice is sometimes difficult → HBPC is an alternative Denial among family/patient Freedom of choice for cardiopulmonary resuscitation (CPR) etc. is important | <ul style="list-style-type: none"> Talks with GP long before service starts, so patients talk more often about it |
| Provider | <ul style="list-style-type: none"> To take care of young patients is emotionally hard on professional caregivers Training and support is important | <ul style="list-style-type: none"> Regular team meetings, talks, for relief of psychological burden of work |

| Domains | Identified barriers | Suggested solutions |
|----------------|---|---|
| | <ul style="list-style-type: none"> • Communication skills are important • Extensive experience of staff improves communication and coordination • Good network/organisation within the team is important (more important than individual skills) • Cooperation between informal and professional caregivers: professional caregivers need to be prepared to step back and hand over responsibility • | <ul style="list-style-type: none"> • Clear distinction between tasks and responsibilities, clear communication between professional and lay caregivers |
| Organisational | <ul style="list-style-type: none"> • Organisation of services is a problem, actually a problem of the NHS as a whole and other institutions/organisations involved in palliative care: services are not always linked together (e.g. lack of communication between everyone involved in palliative care) | <ul style="list-style-type: none"> • Better technical solutions needed → financing needed |
| Funding | <ul style="list-style-type: none"> • Limited resources in UK healthcare system, the NHS is financially squeezed, • Lack of knowledge of funding in palliative care (no data about how much it costs) • Heterogeneity of funding between institutions within England • Financial burden of informal caregivers is huge | <ul style="list-style-type: none"> • Research in financing palliative care is the first step for finding solutions |
| Policies | <ul style="list-style-type: none"> • Increasing awareness of palliative care has led to policies • NHS receives lots of complaints about palliative care (more than anything else) opening a window of opportunity for policies to improve palliative care | |

Table 2 Expert consultation summary findings in Germany

| Domains | Identified barriers | Measures/Solutions |
|-----------------|---|---|
| Geographical | <ul style="list-style-type: none"> • Rural areas are disadvantaged, no access due to long distances for the ambulatory (“specialised HBPC”) teams <p>→ Lower quality due to restricted time of GPs for HBPC</p> | <ul style="list-style-type: none"> • GP would be key person to initiate and conduct basic HBPC • Palliative care centres needed in rural areas • Flexible teams to be at least able to take care of anyone needing HBPC (as guaranteed by law) • More flexible contracts and more flexible models of health insurance cooperation (exemplary model: child HBPC care in Germany) • Big satellite HBPC (German specialised ambulatory palliative care (“SAPV”)) teams = small teams that are affiliated with big team seated in bigger city → prevention of long driving distances, but still in development in few areas, development of well-working concepts needed • Tele-medicine needed (skype, symptom control by mobile phone etc.) |
| Locational | <ul style="list-style-type: none"> • Lacking space is a challenge for HBPC when the patient is part of a big family • HBPC in residential homes for the elderly (also defined as “home” by law) cannot solve existing problems there (lack of personnel, quality of basic care etc.) | |
| Epidemiological | <ul style="list-style-type: none"> • More older people living alone, no possibility of informal care, leading to difficulties to provide (r)HBPC → transfer to old people’s home • Mostly women as informal carers of HBPC patients (daughters, sisters, wives) • Change over past few years that more younger patients with | |

| Domains | Identified barriers | Measures/Solutions |
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| | <p>low SES are reached by HBPC</p> <ul style="list-style-type: none"> • At the moment patients from a war generation that learned to block pain → need for different communication and pain medication • General question if there is actually the need within the target population for a separate HBPC model with focus on reinforced care among patients/families? | <ul style="list-style-type: none"> • Qualifications needed by palliative care staff, especially GPs, to know how to treat/take care of these patients → higher pain medication despite patients not communicating such a need → good provider training needed |
| Socio-cultural | <ul style="list-style-type: none"> • Language barriers: former guest-workers are now in age needing HBPC • No other religions (Muslims, Jews) are reached by HBPC: other culture of dying/family involvement • People from eastern and southern background have different demands for more therapy and not palliative care • Cultural concept of palliative care, as understood by the general population, still does not fit the much broader definition of palliative care, which is much more than pain treatment for cancer patients | <ul style="list-style-type: none"> • Culture-sensitive care: increasing awareness about this topic, palliative care speaking different languages helpful |
| Socio-economic | <ul style="list-style-type: none"> • Inequality in healthcare access also in palliative care for low SES people (vs highly educated people, middle class benefit) <ul style="list-style-type: none"> ○ If people receive social welfare then HBPC is secured because it is paid for ○ Difficult for people with little money as they have to pay/organise for themselves → cannot afford HBPC | |
| Political | <ul style="list-style-type: none"> • Politics facilitate participation of palliative care institutions in policy making via position papers and discussions • Good access to HBPC (this is German specialised ambulatory palliative care, SAPV) is due to regulation implemented in 2007 | |

| Domains | Identified barriers | Measures/Solutions |
|----------------|---|---|
| | <p>which guarantees financing of HBPC by statutory health insurances</p> <ul style="list-style-type: none"> • Categorisation of different care-levels for reimbursement does not equal actual provision (intensity) of care • The health care system may not allow the implementation of rHBPC in the way we define it, as there are different systems of palliative care that altogether make up for HBPC (huge voluntary sector for basic palliative care and “SAPV” for specialized palliative care) | |
| Legal | <ul style="list-style-type: none"> • Reluctance of private insurances to finance HBPC, leading to problems (law suits) who finances HBPC services in some cases • A clear specification of tasks helps to prevent legal problems, in Germany medical decision is always made by the doctor | <ul style="list-style-type: none"> • Standardisation of HBPC |
| Ethical | <ul style="list-style-type: none"> • Assisted suicide is an enormous debate and problematic: <ul style="list-style-type: none"> ○ Knowledge- and communication problem • Lack of knowledge of provider and family about needs of patients in last phase of life: appropriate nutrition, adequate liquids etc. are lacking • Lack of manpower for HBPC could be an ethical problem, although basic palliative care does exist in Germany | <ul style="list-style-type: none"> • Transparency needed/cultural change needed to talk about death etc. • Need to bring knowledge into system: For professionals but also for informal caregivers/families and the patients |
| Provider | <ul style="list-style-type: none"> • No further training for GPs exists • Lack of trained providers | <ul style="list-style-type: none"> • Specific training/education for GPs to improve basic palliative care, will be implemented with new law • Task shifting: e.g. a well-trained nurse could fulfil palliative care tasks (especially in rural areas) |
| Organisational | <ul style="list-style-type: none"> • HBPC in terms of emotional support for family/patients depends a lot on voluntary workers who are integrated in German HBPC system | <ul style="list-style-type: none"> • |

| Domains | Identified barriers | Measures/Solutions |
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| | <ul style="list-style-type: none"> Lack of doctors will lead to problem in HBPC | |
| Funding | <ul style="list-style-type: none"> Not discussed | <ul style="list-style-type: none"> Not discussed |
| Policies | <ul style="list-style-type: none"> Weakness in implementation of 2007 regulation: no specific information what a HBPC team should constitute: federalism and no agreement on criteria by the government leads to heterogeneity in quality of care and financing (e.g. team size ranges from 8-10 to 20 people, different billing systems etc.) New law will be implemented in autumn 2015 to improve basic palliative care <ul style="list-style-type: none"> → more GPs engaging in HBPC → improved quality of care due to more training → effects on financial reimbursement | <ul style="list-style-type: none"> Standardisation of HBPC, more specific legislation |

Table 3 Expert consultation summary findings in Poland

| Domain | Identified barriers | Measures/Solutions |
|--------------|--|---|
| Geographical | <ul style="list-style-type: none"> variability of coverage of HBPC in different regions in Poland (e.g. CARITAS with a very good system operates only in south of Poland (Opole and Down Silesia voivodship) some regions do not have enough palliative care specialists general brain drain in Poland not enough palliative care centres and no clear picture exists (differing between regions) Limited access to palliative care in rural areas <ul style="list-style-type: none"> → better access in cities (but problem of waiting lists; see organisational | <ul style="list-style-type: none"> financial incentives (e.g. tax reduction, EU funding, additional financing) for health professionals providing palliative care at village level |

| Domain | Identified barriers | Measures/Solutions |
|-----------------|--|--|
| | factors) | |
| Setting | Discussed but information later transferred to other domain (geographical) | |
| Epidemiological | <ul style="list-style-type: none"> - Access to palliative care differs according to disease: list of patients who can receive palliative care excludes many diseases (especially non-malignant diseases), such as Alzheimer’s disease or renal insufficiency - Fewer female attendants in social welfare centres - An example from Wroclaw, a big city: most inhabitants are older, many younger people go abroad <ul style="list-style-type: none"> → need for more palliative care → HBPC difficult due to missing generations in one family who could help/provide care for each other - Women usually take over care but they should be supported more by men | <ul style="list-style-type: none"> - Expand list of entitled patients (political!) |
| Socio-cultural | <ul style="list-style-type: none"> - health literacy: lack of knowledge among patients regarding their rights: what they are entitled to receive and which institutions can help them - lack of understanding regarding need for HBPC (“some patients are asking why the doctor arrived for them”) - negative image of palliative care among population <ul style="list-style-type: none"> • some people see palliative doctor “walking with a scythe” - brain drain: less health personnel (doctors, nurses, social professions) stay in Poland but go abroad | <ul style="list-style-type: none"> - media campaign to change people’s opinion about palliative medicine: make them understand the problem and increase awareness in society - help of church: e.g. priests can promote palliative care from the pulpit - raising awareness of term “palliative care” <ul style="list-style-type: none"> → means also treating patients who are not terminally ill but as an alternative when primary care cannot help - Volunteers over 50 years could take care of palliative care patients, they are well-trained and should receive some financial reimbursement |

| Domain | Identified barriers | Measures/Solutions |
|----------------|---|---|
| | <ul style="list-style-type: none"> • Many young people work abroad in England, Germany etc. <ul style="list-style-type: none"> ○ lack of contact among family after family member's death • Children want to leave older parents in hospice because they do not know how to look after them • Women with pain are treated worse than men • Physicians tend to underestimate the pain suffered by patients • As Christians we may not understand other religious rituals, e.g. of Roma | <ul style="list-style-type: none"> - one should pay attention to the role of education and teams - sharing of responsibilities within a family |
| Socio-economic | <ul style="list-style-type: none"> - Per patient 2 diapers a day are financed → problem for those patients who need more | |
| Political | <ul style="list-style-type: none"> • Two Ministries, the Ministry of Health and the Ministry of Labour and Social Policy, are involved with palliative care leading to practical problems such as difficulties in communication and delivery of HBPC <ul style="list-style-type: none"> • e.g. at the moment social workers cannot assist with (r)HBPC • Certain diseases excluded from palliative care, at the moment 90% of patients are cancer patients (excluded: renal insufficiency, COPD, heart failure, Alzheimer etc.) • lack of political support for palliative care <ul style="list-style-type: none"> ○ Palliative care is a topic around All Saints Day only ○ Palliative care for children could be a separate skill ○ palliative care training is insufficient– only 1 short course– and should be changed | <ul style="list-style-type: none"> - Stronger collaboration on national and local level between social (in Poland "MOPS" – Miejski Ośrodek Pomocy Społecznej – A Local Unit of Social Help) and palliative/hospice care - creation of pressure groups to incorporate other disease groups into entitlement for palliative care - Appropriate criteria for admission of patients to palliative care - time may help when politicians' parents will require palliative care → window of |

| Domain | Identified barriers | Measures/Solutions |
|--------|---|--|
| | | <p>opportunity to strengthen and raise image of palliative care</p> |
| Legal | <ul style="list-style-type: none"> • The list of medical services and the drugs needed for specific diseases is strictly limited by the National Health Fund (NFZ) because their costs are reimbursed. One restriction includes, for example, the drug oxycodone which is reimbursed in oral formulations but not for intravenous and subcutaneous route (ampoules). More drugs are reimbursed for cancer diseases but not for others • Only 14 days leave per year are allowed for the care of a family member • Problem with rehabilitation regulations – it is not available when patient is in palliative care – it may only be provided from a palliative care team, whereas it is often for a long time and could be from a local unit • Legal issues regarding cooperative work of social workers and medical personnel due to responsibility of different ministries vs experience in other fields, e.g. schools teachers, dentists and nurses working together successfully • There is a lack of regulations → need to clarify: <ul style="list-style-type: none"> ○ May family administer drugs via the IV and SC routes? ○ especially SC, IV routes (for example in paediatric palliative care parents give children medications via the IV route guided by a palliative care team at home or over the phone) • In case of parenteral nutrition intravenous or pump administration of drugs is not allowed except for neutral liquid. Drugs can only be administered in hospital. • There is serious legal conflict due to 24 hours of care 7 days a week, which breaks the law (a demand of 24/7 work in hospice care versus legal regulation of a maximum of 40h/week) • demand of 24/7 work in hospice care versus legal regulation of a maximum of 40h/week | <ul style="list-style-type: none"> - leave for caregivers should be substantially changed to allow more time to take care of sick family member - more flexible regulation to provide long term care from local units - Clarification of who should manage and finance palliative care: financing is from NFZ (National Health Fund), the legal rules are from the Ministry of Health but the social tasks are run by the Ministry of Labour and Social Policy - use media to pressure politics to change laws for palliative care |

| Domain | Identified barriers | Measures/Solutions |
|----------|---|---|
| Ethical | <ul style="list-style-type: none"> • Unresolved issues associated with do-not-resuscitate (DNR) patients due to lacking regulation • A patient who signed a DNR form, no resuscitation action should be performed. However, DNR orders are not always obeyed as doctors are often afraid of legal prosecution and afraid to talk openly with patients. • Often palliative sedation may be instituted in intractable symptoms, which for example in teenagers is often reversible, many people think that it is “slow euthanasia” • Insufficient psychiatric and psychological care for patients, insufficient treatment of depression • The elderly are often side-lined by society (as patients as well as within the work force) | <ul style="list-style-type: none"> - More education that patients have the right to choose regarding DNR. - awareness/education of society - increase of psychological care in general in Poland - Older people should be included in the care |
| Provider | <ul style="list-style-type: none"> • lack of social workers and nurses working in Poland • inadequate training for volunteers who support patients/families <p>• Undergraduate palliative care education of medical professionals is limited, especially for doctors (better for physiotherapists and nurses), including ethical, interpersonal and interdisciplinary skills to improve HBPC</p> <p>→ lack of knowledge / high quality care</p> | <ul style="list-style-type: none"> - Volunteers should have better training, there should be more people as candidates for volunteers, so we could choose “better” candidates - specification of required minimum number of lectures during medical studies <p>→ So-called “shoes marketing” – means that palliative medicine doctors can educate other physicians when they know each other</p> <ul style="list-style-type: none"> - Implementation of stricter requirements for physicians working in home-based palliative care to ensure quality of care |

| Domain | Identified barriers | Measures/Solutions |
|----------------|--|--|
| | <ul style="list-style-type: none"> • missing communication between palliative care team • students ask for help to learn communication skills • Psycho-oncology is important for palliative care treatment, especially regarding communication with patients • health professionals are overworked • risk of burnout of medical professionals due to job expectations, lack of time and resources and lack of psychological support • need for stricter requirements to provide palliative care (professional experience is relevant for this field) • Several medical universities in Poland have no palliative care units (Warszawa, Lublin, Bialystok – 3 out of 11), in other universities palliative care is taught within other subjects e.g. oncology (Lodz), anaesthesiology (Wroclaw), concerns about quality of teaching with other subjects and limitations of hours; unfortunately, each university is autonomic and has its own curriculum | <p>→ funds for education (funding)</p> <ul style="list-style-type: none"> - training for communication between team (doctors, nurses, patients) - workshops on communication, each doctor should complete a post- diploma course (1 year) in psycho- oncology (available in many universities in Poland) <p>→Financial support for those attending post diploma studies in psycho-oncology and pain medicine (funding)</p> <ul style="list-style-type: none"> - more psychological support for professionals working in palliative care and possibility of additional leave - it would be better to have a minimum curriculum standard for palliative care in each university (see organisational) |
| Organisational | <ul style="list-style-type: none"> • missing cooperation and communication with family doctors (GPs) who know the patients and hospice/ palliative care care, at the moment sole responsibility is with hospital | <ul style="list-style-type: none"> - good example: child palliative care organisation: GPs receive detailed information about patients and have the |

| Domain | Identified barriers | Measures/Solutions |
|---------|--|---|
| | <ul style="list-style-type: none"> • waiting lists in big cities for HBPC due to limited number of patients under palliative care per hospital regulated by contracts imposed by NFZ, if more patients in HBPC programme this is not financed • Lack of some opioids e.g. methadone for intravenous and subcutaneous routes is unavailable, oxycodone rarely used by these routes makes palliative care more difficult • system does not encourage the provision of HBPC (see funding) • There is a special fast “path” for a diagnosis of patients suspected with cancer (“oncology pack” in Polish “pakiet onkologiczny”, for faster diagnosis and quicker access to oncology treatment for patients suspected and then diagnosed (or not) with cancer). At the moment, in Poland there is often a significant waiting time for surgery, radiotherapy and chemotherapy due to the large number of patients and insufficient possibilities of providing treatment for cancer patients. This also refers to waiting for specific investigations such as CT, MRI or PET scans that are extremely important in cancer diagnosis • Bereavement care is limited due to lack of time, finances from national health fund (NFZ), sometimes through primary care („podstawowa opieka zdrowotna“ (POZ), consisting mostly by GPs and nurses for adults, as well as paediatricians for children in out-patient clinics or visiting patients at home)lack of training for psychiatrists | <p>possibility to contact palliative care /hospice units at any time and to meet with hospice staff</p> <ul style="list-style-type: none"> - no limits for patients in contracts - the fast diagnosis path package should be enlarged and include palliative care - Establishment of self-help groups could be helpful |
| Funding | <ul style="list-style-type: none"> • HBPC is financed by the national health fund (NFZ) via a fixed scheme (per day) which does not allow flexibility, e.g. some patients rarely need visits and some more often but the requirement is fixed at two doctoral visits per month and at most 2 visits per week by a nurse independent of the patients’ and families’ needs. • In outpatient clinics: the reimbursement for a visit of the patient in the clinic is the | <ul style="list-style-type: none"> - payment per visit with an appropriate calculation of the finances - additional financing source for doctors and nurses working in small localities /rural areas |

| Domain | Identified barriers | Measures/Solutions |
|----------|--|---|
| | <p>same as when the patient is visited at home → clinics avoid home visits due to financial disadvantage for clinic</p> <ul style="list-style-type: none"> • Funds for medical palliative care are insufficient and society is very dissatisfied with the NFZ as it limits the number of patients treated and often prevents more expensive therapies, e.g. for cancer patients, from being used. • Furthermore the amount of financing for home care patients who live nearby and those who live further away is the same leading to financial problems due to very different transportation costs (rural areas!) • (HB) palliative care system relies on support of sponsors (CARITAS, private institutions, citizens) <ul style="list-style-type: none"> ○ e.g. private institutions donating cars to do home visits or citizens who give 1% of their annual tax to donate e.g. to hospices (for cars, beds etc.) (also socio-cultural) ○ however, of the 1% taxes collected 80% goes to children and only 20% to the needs of older people • The reimbursement is insufficient, especially for patients with non–malignant pain | <ul style="list-style-type: none"> - National Health Fund and funding system should be restructured to improve the financial situation in health care - Generally better financing from NFZ needed, EU funds can be used for 5 years, perhaps own financing system of the palliative care units should be established (not from the NFZ) - Establishment of certified palliative care units by Polish Association for Palliative Medicine (PTMP) that could obtain better financial resources from NFZ |
| Policies | <ul style="list-style-type: none"> • The AOTMiT (“Agencja Oceny Technologii Medycznych i Taryfikacji”- Agency of Assessment of Medical Technologies and Tariffication) assessed the financing of all types of palliative care (home, inpatient, outpatient) in September 2015; not yet known which finances will be available and when they will be implemented (e.g. only in 2017) | |