Submission from the
National Gold Standards Framework (GSF) Centre in End of Life care
on use of the Liverpool Care Pathway (LCP). April 2013

Contents

1. Summary of submission from GSF Centre

- We have supported the use of LCP for many years and it is recommended as good practice within GSF training programmes , used extensively in primary care, care homes, hospitals and other settings
- Use of LCP/ or its equivalent is one of the key standards for GSF Accreditation for Care Homes (Standard 15).
- If the care home, practice or hospital is not using LCP/ equivalent we recommend that the GSF Minimum protocol is used as a checklist to ensure consistently high quality care. We developed this to include the same key areas that are considered in a simple checklist format, it was approved of by John Ellershaw of the LCP team and it has been used for over 8 years in hundreds of care homes and GP practices.
- We undertook a survey of our GSF accredited care homes, seeking their views and experience on use of LCP and the GSF minimum Protocol in their care homes and enclose feedback with results and their comments .
- Overall the findings were very favourable and the care homes find both are extremely helpful and well received by relatives. Usually they use LCP, but some use the GSF MP or both, particularly residential homes supported by different District nursing teams
- Use of GSF was one of the three original EOLC tools , along with LCP and Advance Care Planning , recommended by the NHS EOLC Programme from 2005 and in the NHS EOLC Strategy 2008
- GSF and LCP have worked in a complementary way for over 12 years. GSF relates to care in the final year or so of life, is more of a framework than a pathway and originated in the community (primary care and care homes) where it is widely implemented . LCP by contrast is recommended for the final hours and days, is an example of an integrated care pathway (used in other areas) and initially focussed mainly on use in hospitals
- Use of GSF ensures more holistic care , patients are recognised earlier, included on the GSF/Palliative Care register and leads to significantly greater use of LCP. It benefits people by ensuring that their wishes, needs and preferences (especially for place of care) are recognised earlier and are more likely to be attained.

EOLC Definition- We use the General Medical Council definition of EOLC i.e. final year of life

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

GSF Care Homes Accreditation Standard 15 relating to LCP- of is one of the 4 'must-do' standards that must be passed by all care homes seeking GSF Accreditation and the Quality Hallmark Award . It states:-

1. **Standard 15** ***Care in the final days***

C7 Care in final days – use of a minimal protocol for care in the final days of life or integrated care pathway e.g. Liverpool Care Pathway is mandatory. Evidence includes

- Evidence of use of the GSF minimum protocol / ICP or LCP
- Examples of completed integrated pathway records
- Evidence of care given and monitoring of residents in the dying stage
- Evidence of provision to ensure resident doesn't die aloneHome policy on care of the dying.

2. About GSF and the work of the GSF Centre

The National Gold Standards Framework (GSF) Centre in End of life care
Is the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life. GSF improves the quality, coordination and organisation of care leading to better patient outcomes in line with their needs and preferences and greater cost efficiency through reducing hospitalisation.

The National GSF Centre for End of Life Care provides training programmes that enable generalist frontline staff in health and social care to provide a 'gold standard' of care for all people nearing the end of life.
We do this in a wide range of settings by providing:-

- Quality improvement training programmes and quality assurance Accreditation
- tried and tested resources, guides and tools,
- evaluations - measures and metrics, comparative and benchmarked
- and local support for best implementation and cross-boundary integration

Our Mission Statement
Our aspiration is to deliver training and support that brings about individual and organisational transformation, enabling a 'gold standard' of care for all people nearing the end of life.

"Every organisation involved in providing end of life care will be expected to adopt a coordination process such as the GSF" Department of Health End of Life Care Strategy 2008

GSF is a systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by generalist care providers. Use of the Gold Standards Framework improves the quality, coordination and organisation of care, leading to better patient outcomes in line with their needs and preferences, and greater cost efficiency through reducing crises and avoidable hospitalisation.
We provide tools, skills and resources for the usual generalist care provider to enable them to give better care for people nearing the end of life, and better work with specialists. This includes care:-

- For people considered to be at any stage in the final years of life
- For people with any condition or diagnosis
- For people in any setting, ' in whichever bed they are in,'
- Provided by any person, health or social care professional
- At any time needed.

GSF supports

- **quality improvement -through training programmes in many settings and subjects**
- **quality assurance – with evaluation and benchmarked audit measures**
- **and quality recognition - through the GSF accreditation process, working with independent partners in the relevant sectors such as RCGP , care homes organisations etc**

GSF programmes used in many settings

1. GSF Primary Care- *since 2000 Foundation Level GSF mainstreamed in 95% practices- 300 having done Next Stage GSF Going for Gold –Practice Accreditation underway supported by RCGP*
2. GSF Care Homes- *since 2004 over 2,300 care homes trained and 5 years of accreditation process*
3. GSF Acute Hospitals- *since 2008- 32 hospitals, 5 whole hospital, independent evaluation , accreditation 2014*
4. GSF Community hospitals – *since 2011 28 hospitals involved – first accreditation Sept 2013*
5. GSF Domiciliary care – *since 2011- 3 pilots- over 300 carers - train the trainers programme*
6. GSF Dementia care- *March 2013- first 60 delegates supported by DH Dementia Strategy group*

- In development – *GSF hospice care, prisons, spiritual care, bereavement etc*

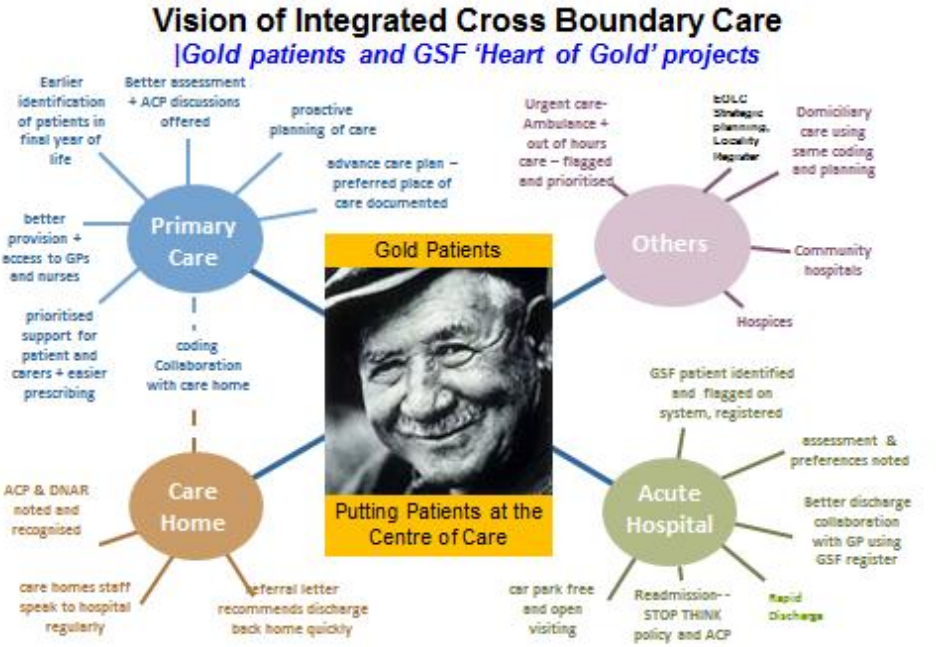
The GSF Five Gold Standards

- **Right person** – *identifying the population, communicating this to others*
- **Right care** – *assessing needs, preferences and care required + providing services*
- **Right place** – *reducing hospitalisation enabling more to live and die at home*
- **Right time** – *proactive planning, fewer crises, predicted care in final days of life*
- **Every-time** – *consistency of practice*

Benefits of being a 'GSF 'patient

Being recognised as a 'gold' or 'GSF' patient should lead to many benefits for patients, their families and staff caring for them in their different settings, leading to well integrated cross boundary care. These benefits include:

Benefits to patients, family and carers	Benefits to staff and system of care
• Earlier recognition + planning of care – fewer crises • Better consideration and communication of their needs wishes and preferences • Better care at the GP practice e.g. GP responses/ visit , reception staff being more aware of needs, • Empowering of patients and ability to have choice and retain control • They are offered advance care planning discussions, recorded + communicated to others • They may have a card /leaflet, to help direct others involved in their care and improve coordination • They are more likely to receive quicker response eg OOH and the proactive services they wish for e.g. domiciliary care, respite, carer support etc • This leads to reduced hospitalisation and more dying where they choose • Financial Benefits – e.g. DS1500 and others more likely to be completed • Greater awareness of spiritual needs • Open visiting and free car parking	• Improved systematised working, so more consistent and less dependent on few key people • Staff feel more confident and able to have more open discussions with patients and families • Improve cost effectiveness and reduce unnecessary hospitalisation or wasting of resources • People nearing the end of life are identified early and registered on the GP's GSF/ QOF palliative care register - this may lead to registration on the EPACCS or Locality Register in some areas . • Provision of services for quicker response from the Out of Hours service as a vulnerable patient e.g. they will be phoned back in 20 mins in some areas • They may be flagged up on the IT system of the hospital – so if readmitted or come to A&E • Redesigning of services to increase community support • Improved audit and monitoring of systems



3. Findings from GSF Survey on use of Minimum Protocol and LCP for care of the dying in GSF Accredited care homes - March 9th– April 9th 2013

(See also Survey questionnaire and GSF Minimum Protocol included at the end of survey results in Appendix)

Currently 116 responses from care homes staff from GSF Accredited care homes- undertaken during Accreditation conference March 7th and postal survey following this – (some answered only a few relevant questions)

GSF Care homers training has been running since 2004 and over 2,300 care homes have been trained. This takes about 9 months with 6 workshops. Recommendation of use of LCP or GSF Minimum Protocol has always been part of the GSF programme. Over 400 care homes (nursing and residential) have been GSF accredited- and GSF Care Homes accreditation is recognised by CQC and leading commissioners.

Key messages from survey

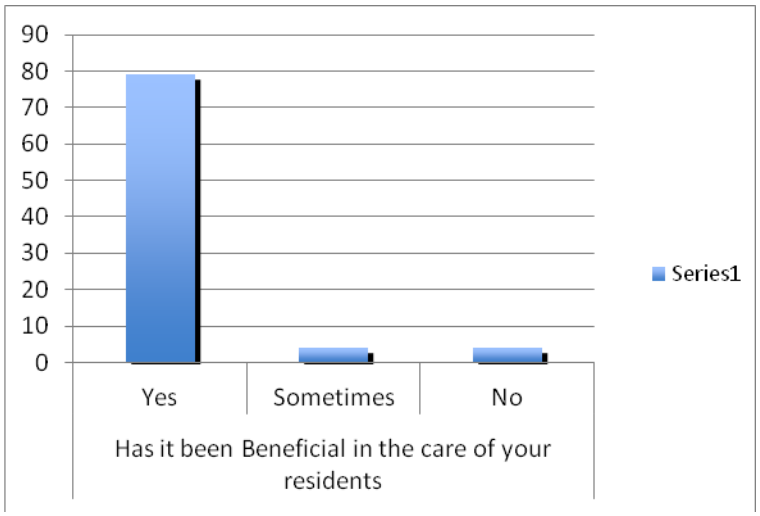
- **This Survey**. Most of the 116 respondents from GSF accredited care homes use LCP (79)or local adaptation (16) and 26 respondents use GSF Minimum Protocol only. However many care homes use both together – with different patients or at the same time , and therefore the number of responses varied (and those responding to question 2 did not correlate with numbers in question 1)
- **Overall** use of LCP and GSF Minimum Protocol are thought to be of considerable benefit to patients / residents and well received by their relatives.
- **Use of LCP**- There have been some issues with media portrayal and queries from relatives about LCP , but most care homes are very satisfied with its benefits and use and feel they take the opportunity to discuss this fully issue with the relatives – see comments
- **Use of the GSF Minimum Protocol**- this is an alternative basic checklist used for care of the dying, along the lines of LCP and with similar goals but more as a practical means to ensure everything is done at the right time. It is used where care homes are not using LCP/ alternative and is not in competition but seen as complementary. The absence of any such plan/ pathway is not acceptable with the GSF Programme or Accreditation of care homes- both nursing homes and residential homes ie all must do something .
- **The GSF Minimum Protocol** (see appendix) has been successfully used by a number of care homes with great perceived benefit to residents, satisfaction for relatives and very few problems or difficulties. It might therefore be an alternate for some who do not wish to use LCP. It is of particular use with non- clinicians in residential homes and should be considered as a possible alternative. It also however does require training and discussion with family and relatives is essential, but on the whole is less threatening for some and possibly less likely to lead to complaints or difficulties. Further discussion and information can be provided

NB Below are the anonymised findings from the survey respondents and their comments taken direct from the survey questionnaire (for survey see Appendix).

Results

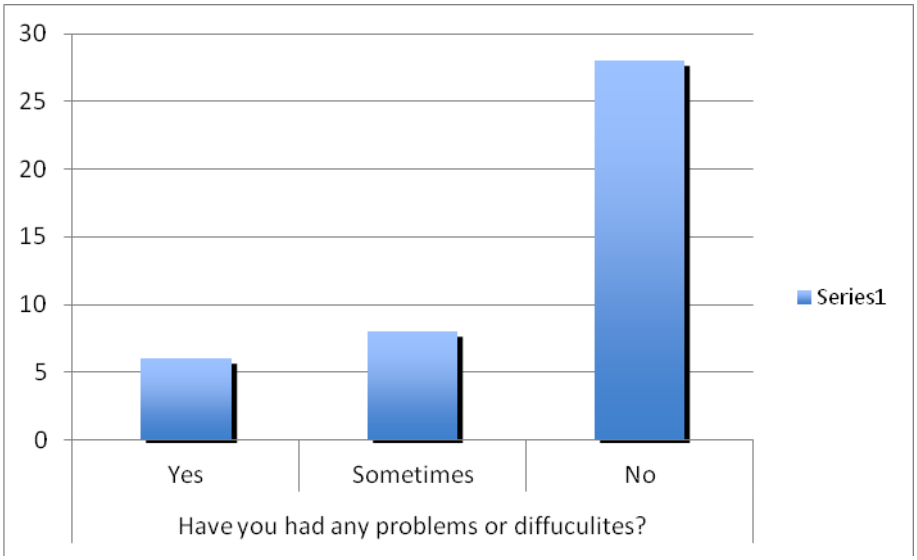
2.Q2. **Use of GSF Minimum Protocol**

a) Benefit



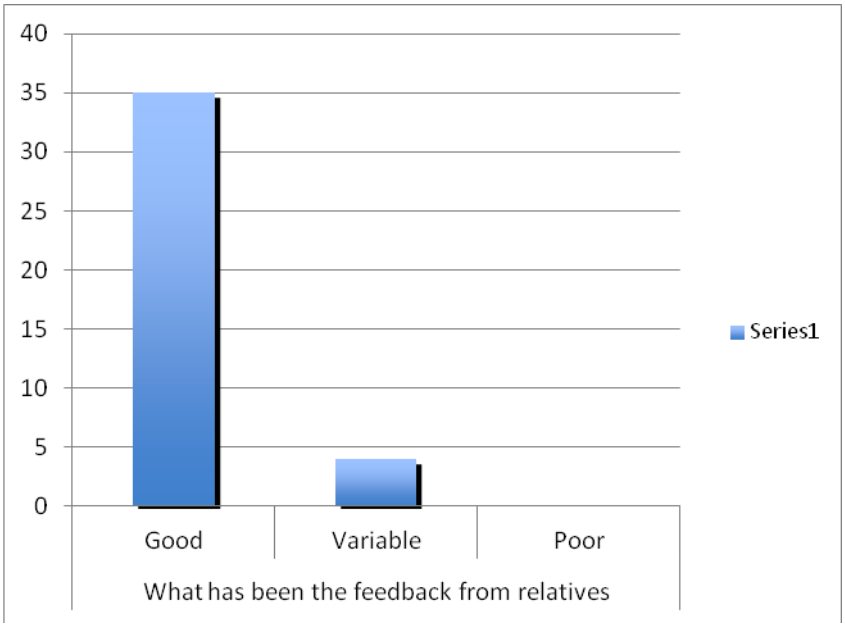
If Yes please describe
reduces suffering for our residents
Easy to follow. Acts as a prompt.
it ensures that all aspects of end of life care are well co-ordinated
allows good preparation for onset of E.O.L
it provides a structure that means nothing gets forgotten
acts as a prompt and guidelines for our care
to promote a peaceful death
enables us to keep everyone informed/ in the loop
all levels of carers - nurses are involved
Our collaboration with the MDT has improved greatly. This has made it easy for everyone to participate in the care of the resident in a timely manner since all our MDT are aware of the minimum protocol
It has helped us to identify what other services we would need to support service user with end of life care. It has supported staff in providing good quality end of life care.
Very helpful reminder for staff. A prompt to promote care.
It has helped to join up the dots of what was good care to become excellent care
Evidenced benefits to residents
Helps in a good death
Evidence to good deaths
Has reduced the need for hospitalisation
It enables us to be proactive not reactive
it is simple focussed, easy to use but covers all the prompts for all main areas
provides useful checklist and prompts for novices
to monitor pain, restlessness, agitation and the condition of the resident
meeting end of life needs of residents
everyone is aware of the tool which brings consistency
increase knowledge/confidence of staff, residents and relatives
it helps to reduce hospitalisations, peaceful death, peace of mind for client
it has given residents the opportunity to make end of life decisions and given staff confidence to implement these choices

b) Problems



If Yes please describe
failure of GP prescribing in a timely manner
GPs at times reluctant to prescribe antic meds or do DNAR, if lacking capacity
initially with GPs and out of hours but not now
the design had multiple questions in on box-redesigned IP per box
Family understanding
G.P. support initially
family want resident to have active treatment
Liaising with GPs, anticipatory medication
getting staff to remember to complete paperwork
1 patient in red was discharged from hospital with no DNAR or drugs. Incorrect prescription for syringe driver. GP reluctant to prescribe anticipatory meds. In amber

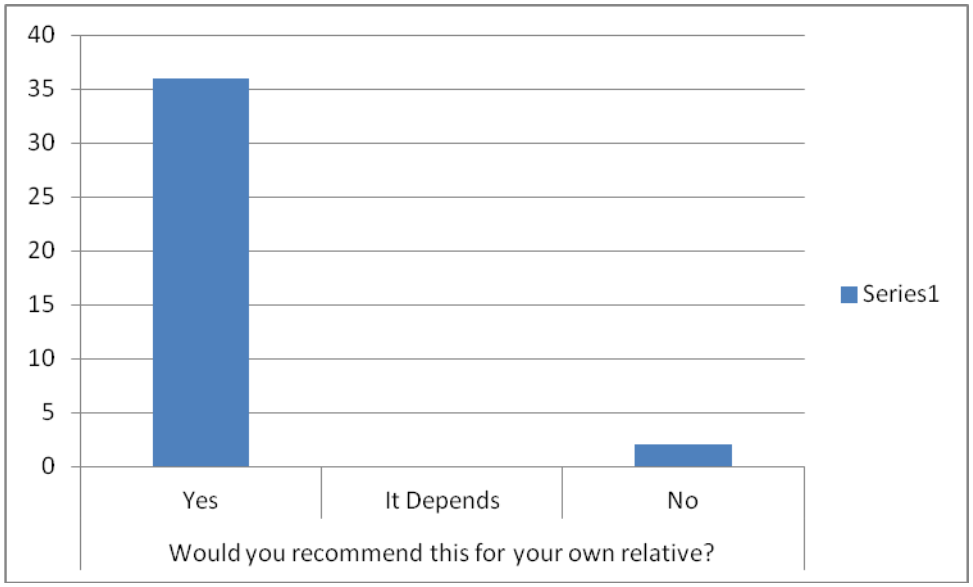
c) Relatives feedback



How do you communicate with relatives ?
full consultation family and GP care home staff
Discussions booked with relatives
we try to work in partnership with our relatives and sit and discuss all aspects of end of life care with them
Face to face with the family. Leaflets ACP LCP
we talk to the relatives and also provide leaflets explaining the dying process
by discussing it with them
discuss the tool very carefully
at visits - good communication with families keeping them in the loop
gives them a greater understanding of final days
Whenever a residents code and condition changes, staff hold a mini MDT's with the family to give them information and support regarding the next steps in care. After which, the named nurse and key worker for the family will keep in touch with the family daily depending on preference
discussion groups and their involvement
it is discussed as part of the advance care planning discussions we have with relatives
Always explain LCP or MP to relatives and give them information leaflet to explain. Relatives have said they like to have the information leaflet to read
Some relatives still worry due to media reporting
At all stages, pre-admission, admission and care reviews
Honest and open
Open communication
Email letters notice board individual and group
verbal telephone and face to face
developing a good rapport offering support and guidance
advanced care plans, updating them of any changes
brochures and meetings
aim is to have a face to face meeting within 2 weeks of admission or earlier if in amber or red
from memorial book comment and thank you cards

face to face, resident surveys and via the telephone

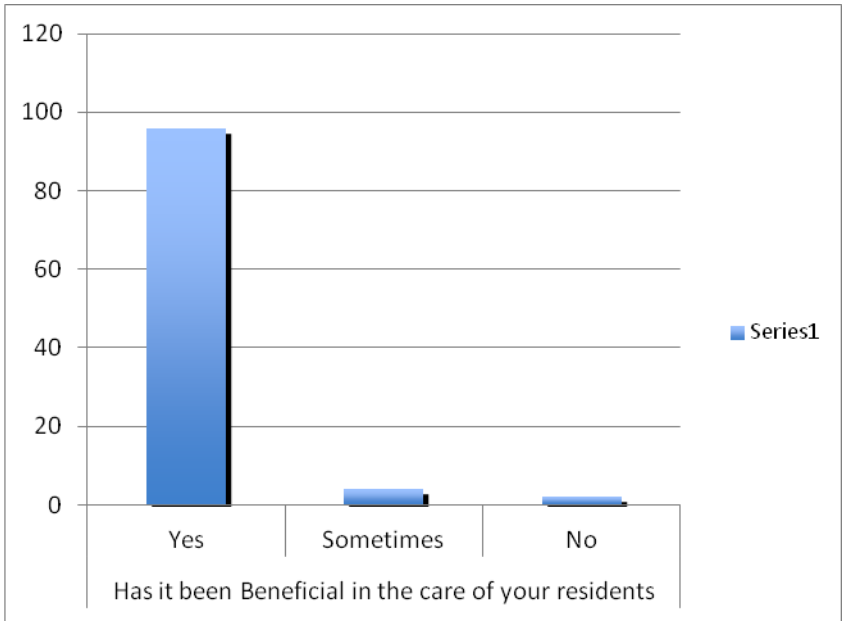
d) Would you recommend it?



Please give any relevant details from your experience
my own mum was nursed in this way and had a peaceful death
Without a doubt and already have. Success is sometimes dependent on external professionals
I would like my mum to be safe, warm and comfortable in her last hours. I would also want her to be treated with dignity
my father in law was on it
gives a good standard of care - encourages staff to be proactive
carer had completed ACP and wishes were followed
Relatives seem to have confidence in our staff when they see that there is a process in place. The protocol has also made it easy for staff to prepare for a good death. This means that they are in the best position to also prepare the family
having the gold standards framework in place for 2 years we have found that having this standard has enabled us to support service users with end of life care while support the relatives with dealing with the death of a loved one.
insufficient detail to provide follow on care
To ensure good quality care in my relative last days and life
NHM has 1:1 with the relative
Future planning. Resident has peaceful death. Wishes of resident met and choice of place of death
We monitored a resident closely who was showing signs of pain on movement, we contacted the general practitioner and the palliative care team. It proved very beneficial as using this record enabled the staff to act promptly
dignified peaceful death
good positive outcomes for residents
my relative is in the nursing wing
family and friends were able to hold the clients hands at the time of death
staff moral home has improved considerably and there is trust, respect and confidence between staff and families

Q2 Liverpool Care Pathway

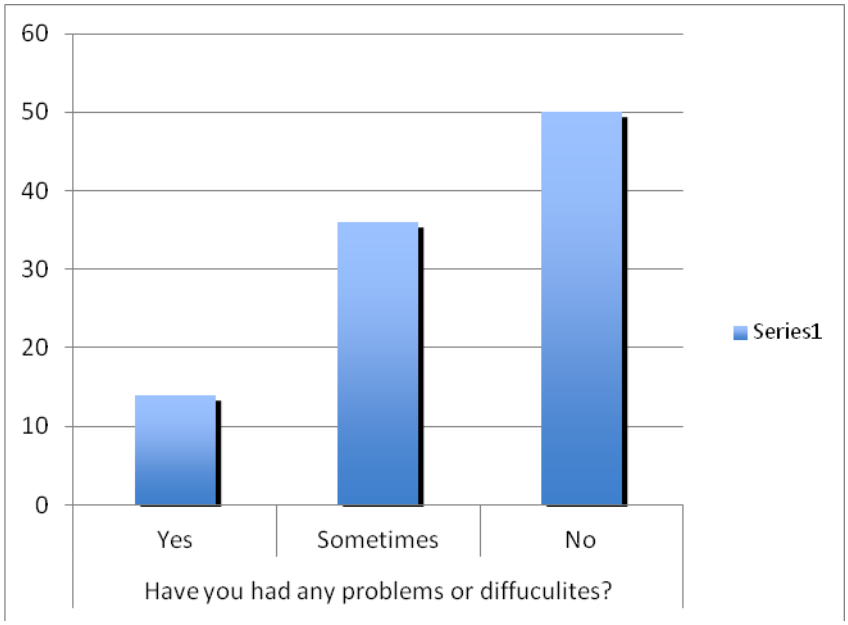
a) Benefit



If Yes please describe
provides prompts to ensure all needs assessed
When explained what is for and why and consent gained before starting
allows for a peaceful death with the family being fully informed
We have used the Liverpool Care Pathway or a variant of it for approximately 10 years. This tool has been an excellent document which I highly recommend.
Focus on their needs. Improve quality of care
Allowing trained nurses and carers more time to give full appropriate bedside care instead of worrying about full care.
In our area, the District Nurses instigate the LCP. The paperwork is quite unwieldy and they do not always have the time to complete. In these circumstances, we always use the GSF minimum protocol that I find to be a more efficient and effective checklist. Also, the LCP has been used less since the adverse publicity in the media.
ensures that all areas of End of Life Care are covered
correctly followed it provides a peaceful dignified death
the LCP has been surprisingly well accepted by relatives and also the staff here. It ensures continuity of care and symptom control which is good for the resident
assists in a structured approach to control symptoms and provide a dignified end
has ensured our residents received appropriate care at EOL
used properly with explanation no problems
it helps to identify any problems so they are addressed
paper exercise in-house documentation better
LCP focuses the staff to give excellent care 24/7
format allows staff to be reminded of appropriate care to give thus benefitting resident
co-ordinates focus of all staff, ensures everyone evaluating patient as a whole
Focusing attention and identifying needs if any

Generally a guide for best patient care
All staff/ relatives are able to be part of care and document it
It shows evidence of good care given in the dying phase
One system of paperwork
Delivering more effective care
Consistency of care
Continuity of care-detailed monitoring of symptoms
Enables a peaceful death. Everything in place efficiently
Focuses on comfort and rules out unnecessary intervention
Frequent monitoring. GLP visits and palliative care nurse input yearly anticipatory meds
Staff would assess same information anyway-formalises the process
in relieving symptoms/ pain relief
more user friendly i.e. easy to follow - small changes to LCP
resident have peaceful death, wishes of resident met and choice of place of death
enables you to focus/ concentrate care needs in one document; focuses on what is important, acts as a prompt
Anticipation of needs. It has enabled staff to focus on the complete holistic care
focus on care through the residents EOL
residents are more comfortable with symptoms controlled
reduced hospitalisation, enables residents to die in preferred place
LCP used on occasions instigated by community nurses. Used much less due to negative publicity
helps ensure get equitable care
focuses holistic care
covers all aspect of care
to provide high quality of care at the end of life and to help our residents to have a peaceful death
planning treatment/relief of symptoms
promoted good end of life care
document acts as a prompt - easy to see variances as a quick guide
Ensures that all aspects of end of life care are covered and nothing is forgotten. Consolidates all the care needs into one package that is easy to understand.
especially when syringe driver being used as regular checks
It has improved care for the residents in the last days or hours of life. It has provided pain free comfortable and dignified death
able to provide excellent care according to clients choice and gets peaceful death
needs anticipated dignity in death
it ensures staff think about all aspects of care and involves the family in that care

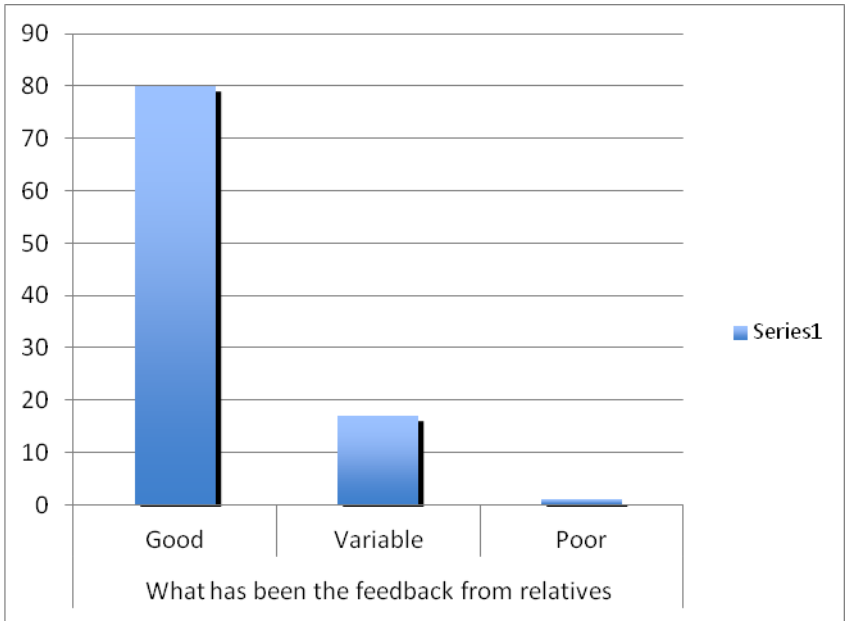
b) Problems?



If Yes please describe
GP completion
The only difficulties we have had is since the negative publicity
education and training of staff
only ensuring that all staff use the most updated version
due to recent media attention and given false impressions of LCP
GP's completing their entries and reviewing regularly
equipment failure identified by variance checklist
ensure all staff clear on how to complete the LCP
Mainly in the past, due to GP reluctance, but this is now standard practice.
only difficulty has been getting GPs to visit as required
but nothing beneficial
sometimes the recent bad press has prompted relatives to need more reassurance about its use and why we use it
Reluctance of some GP's to complete initial assessment.
D.N saying we weren't allowed to write on L.C.P Using
Sometimes relatives refuse to give consent for use of LCP due to media report.
DN reluctant to implement it
Anticipating when to start
Relatives anxieties due to media
Relatives differing opinion of LCP and ethical issues for media. Staff comprehending impact of LCP on dying individuals
occ. reluctance by primary care team to use since poor press
some primary care teams are reluctant to use
getting doctors to sign it

in residents unit they have to wait for GP or DN to complete
district nurses not filling in properly
reluctance from some GPs to sign LCPs following adverse publicity
with some families
relatives starting LCP (EOL) depending on GPs
initial reluctance from staff to use it - resolved training
negative publicity
mostly because of the way the LCP is communicated to families and when staff use it regimentally
district nurses were initially not keen to allow care staff to record it
asking GPs to update it as frequently as required
GP participation
does not offer prompts for everything e.g. jewellery
have had difficulties in the past getting residents put onto the LCP as some nurses don't like the paperwork involved particularly if it appears the resident may pass away in a very short space of time
now have LCP means relatives get very nervous
delaying to start LCP due to lack of GPs coordination and awareness of pathway
The bad press in the daily mail has frightened family and carers. I have had to go through the LCP with carers to reassure them

c) Relatives feedback

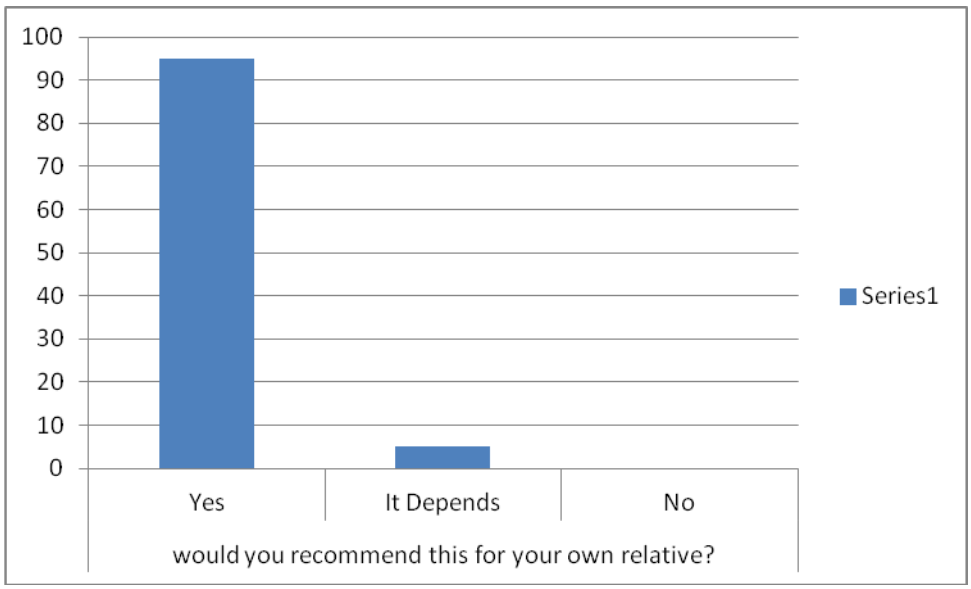


How do you communicate this with relatives
Plans for open afternoon to discuss GSF and LCP
Give front sheet and have discussion with relative and GP
discuss reasons, multidisciplinary approach
only recently started using the integrated care plan
by talking to them; supporting them and explaining to them the documentation - this is backed up by leaflets we have designed and give to the relatives
usually face to face but sometimes over the phone
keep them involved every step of the way

personally, I sit down with the family and introduce it fully
In our area, if the District Nurses decide to use the LCP, they would discuss this with the relatives. In reality, the LCP is rarely used these days.
Verbally. Written and following surveys
we discuss with relatives and residents
Face to face with family/carers. Full discussions
verbally
relatives talk about their feelings openly
full explanation of the tool given to relatives prior to commencement
sit with relatives and fully explain the LCP prior to commencement
LCP communication with relatives at the start of the LCP
via a leaflet we made from the front page of the LCP
concerned over its initial being used until reassured
relatives ok with adequate prompt explanations from staff
involve them from advance care planning process through to end of life
Thorough explanation of its use and involvement of relatives
explained in advance relatives kept informed
Inform them about LCP prior to need, keep them all the way.
Constant communication and involvement
All knew what to expect and were able to have input
They are usually appreciative that their loved ones died peacefully
Talking to them
All methods
Personally face to face
One to one dialogue, literature, involve GP
relative communications with LCP starter
information/explanation of LCP to relatives prior to use is essential
from pre admission - leaflet then discussion
I have gone through paperwork prior to starting LCP
we have to discuss the situation privately and sensitively
district nurses followed by home staff
only recently started using this tool - positive comments so far
Through GP staff and relatives meetings. Leaflet attached to LCP for relatives
we use information leaflets but they key is having a good relationship
relatives have said that their loved ones looked calm and peaceful
one to one - leaflets
verbal and telephone/face to face
full explanation of the record, showing them how we use it
explaining about LCP and providing leaflets
phone, man, verbal discussion
continuity of care
verbally and through our quality assurance questionnaires
most relatives understand the paperwork - some who have read the recent bad press will not even look at it or listen to explanations
Relatives are kept fully informed of their family member's condition and all changes are explained to them. The LCP and the care the resident requires will be explained either by a senior staff member or a member of the nursing team. Not all relatives are interested in the paperwork but many chose to help with the actual help of the dying person

depends on relatives understanding
encouraging them to ask questions
from the comments book and memorial book and thank you cards
face to face
discussion
I sit down with relatives and discuss what we are going to do, before we start, at each stage

d) Would you recommend it?



Please give any relevant details from your experience
Needs to be implemented at the correct time and only after discussion with resident/ relative
families don't have to see a relative suffering as all medications for symptom relief are in place
dependent on where they were
nurses found this tool to be suitable for its purpose
my father was on the Liverpool Care Pathway, I was very pleased that he was
like any tool it depends on the user, the LCP (amended or otherwise) can enhance end of life care
focuses on the needs of the dying person
some relatives require further support and explanation due to negative media cover.
the LCP is an effective tool if used properly by trained staff
LCP has been used here for 5 years and so has become part of our paperwork for End of Life Care.
Audit of death data for 2012 showed 40% of all deaths at the home on the LCP
ensures a flow of care and easier to trace medical input
we know our residents the LCP is excellent for Nursing Homes
used LCP when my mother was dying and found it a good checklist that helped assess symptoms. Were well controlled
all clients treated with correct care and GP supported
LCP helps to ensure the client's needs are being met
no if it was a GSF accredited home as would feel assured of quality and processes. Yes if it was not a GSF accredited home
relatives appreciate getting them fully involved, seeing that all decisions are made in best interest of patient and in looking towards ensuring comfort is priority

Danger that LCP or any such tool can be seen as a tick box exercise and either miss-used or miss-understood- must be backed up with nursing notes.
Promotes good nursing practice and communication
Used correctly L.C.P. is a very effective tool to providing a comfortable, peaceful end of life. The users of the tool are paramount to its good use.
I have completed an ACP but my mother and _____
I have actually informally organised it for my late sister who died recently abroad and she died at home in the hands of relatives
Whether I resumed it depends on the care and what is in place
general hospitals are extremely poor using LCP and communicating
used on CNS prior to current role - used appropriately - very good
I was not aware whether hospice used it. Pain control must have been better both parent in hospice
staff of relatives got more prepared
it organises care - staff feel useful and know what to do
I have worked in spec. pal. Care. In acute trusts, hospice and community services
families found the leaflets good - can look at them in their own time - do not always take the information in at first
when we use the document it assisted with all aspects of care from different professionals which proved very good from communication
ensure that our residents spiritual needs are met and helps in respecting their dignity
if used correctly is an excellent tool for all of the multi-disciplinary team
client will get preferred place of death and wishes as per choice
Residents are pain free and changes in condition identified immediately. Community specialities also able to respond quickly
In the past the LCP has just enhanced our job, ensuring nothing was missed. We are considering using the GSF minimum protocol much more, especially with those families who do not want us to use the LCP

4.APPENDIX - GSF Care in the Dying Phase - Minimum Protocol for Care in the Final Days

Name of patient .....Date ..... completed by.....

Check list	Achieved	To do	Not appropriate
1. Diagnosis and recognition of dying –awareness of signs of terminal phase ▪ Agreement by clinical team ▪ Bed bound / increasing sleepiness, semi conscious / only taking sips of fluids / not taking oral medicines/ other factors			
2. Advance Care Planning ▪ Use of an Advance Care Plan / Statement with preferences/statement noted and respected ▪ DNAR discussed, noted and communicated to others ▪ Other refusal of treatment / Advance Decision if appropriate			
3. **Medication re-assessed** ▪ Non-essential medication discontinued ▪ Essential treatment converted when appropriate to subcutaneous route via syringe driver/transdermal/sublingual route*)*			
4. **Anticipatory medication - PRN** ▪ Standard protocol for 'as required' medication for the dying phase written up and available, including pain, agitation, respiratory secretions, nausea and vomiting and breathlessness.			
5. **Spiritual, religious needs** ▪ Spiritual and religious needs assessed and met regarding patient and carers ▪ Support from clergy or other spiritual advisors			
6. **Ongoing assessment** ▪ Regular assessment of symptom control (pain, agitation, respiratory tract secretions, mouth-care, pressure areas, psychosocial support) ▪ Evaluate care plans for all care including mouth-care, pressure relieving for comfort, urinary management etc.			
7. **Family awareness** ▪ Family / carers are aware that the patient is dying ▪ Family to be enabled to be involved in some patient care, if appropriate ▪ Family contact increased - arrangements for contact before / at time of death confirmed and practical arrangements arranged eg staying overnight ▪ Ensure information provided eg pre-bereavement care, advice sheet			
8. **Communication** ▪ To GP in hours and handover form for out-of-hours providers ▪ Other residents prepared ▪ 'Expected death' form: Code 'D' - expected death discussion - recorded and signed. Local policies / guidelines followed			
9. **After care and bereavement** ▪ Verification of death procedure and funeral director notified ▪ Staff protocol for after-death care - religious / cultural rituals ▪ Follow up care for family - leaflet / information for relatives, access to bereavement support services ▪ Support for residents eg Memorial Service / acknowledgement ▪ Secondary / specialist services informed and hospital appointments cancelled after a death ▪ Support and debriefing for staff			
10. After Death Analysis ▪ ADA complete audit ▪ Significant event analysis - reflection in practice			

Or use an integrated care pathway for Final days / Liverpool Care Pathway

GSF Survey on use of Minimum Protocol/LCP for care of the dying

in GSF Accredited care homes - March 2013

Name: ……..Care Home: …… Role ……Date: ……

If you use the GSF Minimum Protocol/LCP/other care pathway/plan for dying residents in the final days of life-

1. **Which one do you use for most dying residents in your care home?**
   - GSF Minimum Protocol ☐
   - Liverpool Care Pathway ☐
   - Adaptation of LCP- (please state) …… ☐
   - Other (please state) …….. ☐
   - We do not use any of these. Why not?..... ☐

2. **If you use the GSF Minimum Protocol for care for the dying please answer below-**
   a. Has it been beneficial in the care of your residents? Yes ☐ Sometimes ☐ No ☐
   b. If so please describe.
   ……
   c. Have you had any problems or difficulties? Yes ☐ Sometimes ☐ No ☐
   d. If so please describe.
   ……
   e. What has been the feedback from relatives? Good ☐ Variable ☐ Poor ☐
   f. How do you communicate this with relatives?
   ……
   g. Would you recommend this for your own relative? Yes ☐ It depends ☐ No ☐
   h. Please give any relevant details from your experience
   ……
   i. Any suggestions for further improvements?
   ……

3. **If you use the Liverpool Care Pathway or an alternative please answer below -**
   a. Has it been beneficial to your residents? Yes ☐ Sometimes ☐ No ☐
   b. If so please describe.
   ……
   c. Have you had any problems or difficulties? Yes ☐ Sometimes ☐ No ☐
   d. If so please describe.
   ……
   e. What has been the feedback from relatives? Good ☐ Variable ☐ Poor ☐
   f. How do you communicate this with relatives?
   ……
   g. Would you recommend this for your own relative? Yes ☐ Sometimes ☐ No ☐
   h. Please give any relevant details from your experience
   ……
   i. Any suggestions for further improvements?
   ……

4. **Additional comments from your experience**

……

All survey replies will be analysed by the GSF Centre in confidence, as part of an anonymised report, and will be used to help to improve care further. Your feedback is much appreciated. ***Thank you.***