

We need to talk about Palliative Care

Ardgowan Hospice and Inverclyde Health and Social Care Partnership

Joint Submission in Partnership with

Inverclyde Royal Hospital Specialist Palliative Care

Inverclyde in Partnership for Palliative Care

Introduction

Inverclyde has the smallest Health and Social Care Partnership (HSCP) in terms of population within Greater Glasgow and Clyde, having a population of 79860 (mid-year Index 2014 data). In 2013 it was estimated that 33,777 people were living within the SIMD ID category of SIMD 1, the most deprived quintile. There are also increasing numbers of single households where people are known to receive pensions, making up 16.2% of total pensionable numbers. National Records of Scotland hold data stating that Life Expectancy in Inverclyde is 1.3 years lower for men and 0.3 years lower for women than the Scottish average. Inverclyde has one District General Hospital, Inverclyde Royal Hospital and an 8 bedded Hospice Unit providing Specialist Palliative Care, Ardgowan Hospice. The hospice also has a health and wellbeing centre and a specialist outreach nursing service. Health and social care is co-ordinated by Inverclyde HSCP. There are 16 GP Practices and a Hospital Specialist Palliative Care Team based at Inverclyde Royal Hospital.

Access to Palliative Specialist Care is a right of all individuals living in Inverclyde and who would benefit from this. It is the focus of Palliative Care Services that we reach out to all people with Palliative Care Needs. Services within Inverclyde have a key focus of partnership working and collaboration between Health and Social Care as well as third sector organisations. This is paramount to the ongoing delivery of quality Palliative Care for patients and their families and carers within Inverclyde. Our strengths are partnership working and sharing of information, education delivery and our ongoing enthusiasm and innovation. All these factors are key drivers for development and positive change within and across organisations. Indeed Inverclyde is striving ahead with creativity, enthusiasm and innovation, aiming for best quality health and social care.

1. What has been your experience in terms of access to Palliative and End of Life Care?

- 1.1 Ardgowan Hospice Research and Improvement Fellow, Dr Caroline Sime, is currently undertaking a significant piece of work in order to research referral pathways into Specialist Palliative Care within Inverclyde. At present, the internal pathways for referrals are being process mapped. Work has started to engage with primary care staff (GPs and District Nurses) to identify where this works well and also to highlight where there are barriers to timely referral within the current pathway.

- 1.2 Dr Sandra McConnell, Consultant, Ardgowan Hospice; Dr Caroline Sime; Dr Jill McKane, GP, Palliative Care Facilitator; Mrs Alison Bunce, Director of Care, Ardgowan Hospice; Mrs Christine Hennan, Nurse Team Leader, Adult Community Nursing, Inverclyde HSPC; and Mr Braidwood, Project Manager, Inverclyde HSPC are undertaking joint research examining Inverclyde GPs triggers for Inverclyde Specialist Palliative Care Services referral. This is a subsection of a larger project to further assess and improve on communication and links between Specialist Palliative Care and Community Teams. Ardgowan Hospice will involve GPs, District Nursing Service, Inverclyde Royal Hospital Palliative and Social Work Social Care Teams and other relevant stakeholders when shaping the future of their services to meet local requirements.
- 1.3 Dr McKane, Dr McConnell and Dr Sime are conducting joint visits to all local GP surgeries in order to foster links between community and Ardgowan Hospice services. This will provide the opportunity to vitally signpost local GPs to the availability of services at Ardgowan Hospice. It will address anecdotal evidence that some referrals, specifically patients with non-malignant conditions, could in some cases have benefited from an earlier referral. As part of this signposting exercise, The Palliative Care Resource Packs, within all GPs surgeries, collated jointly by Dr McKane, Dr McConnell, Mrs Hennan and Miss Elayne Harris, Lead Palliative Care Pharmacist, will also include prognostication tools. GPs are offered regular Palliative Care evening education sessions which include discussion around all these topics and again foster good team working and networking within Inverclyde services.
- 1.4 An educational needs assessment survey of local GPs was completed in 2014 by Dr McKane in collaboration with Dr McConnell and Dr Stuart Milligan, Ardgowan Hospice Educational Facilitator.
- 1.5 A Rapid Discharge Pathway has been piloted within Inverclyde Royal Hospital. The wards involved in this pilot were G North (Medical) and H South (Surgical). Based on audit site results and despite the limited numbers involved, the pathway was disseminated to all IRH wards earlier this year.
- 1.6 [Your Voice](#), in collaboration with Dr Milligan and Dr McKane, provide an ongoing updated list of *Inverclyde Directory of Services (updated 2014)*.
- 1.7 Ardgowan Hospice accept referrals from a variety of Health and Social Care professionals. These patients are all reviewed within adequate time frames and supported by a range of appropriate services. The hospice are actively exploring the use of their website for self referrals.
- 1.8 Needs assessments and action plans: *Ardgowan Hospice 30th Anniversary Report and Inverclyde Palliative Care Needs Assessment carried out by Dr Jacquelyn Chaplin* in 2013. See also most recent

action plan (2014) from the *Joint Inverclyde Palliative Care Group (JIPG)*, a group chaired by Dr Milligan; lead names have been omitted for discretion.

- 1.9 Ardgowan Hospice Clinical Nurse Specialists attend Multidisciplinary Palliative Care Meetings within GP surgeries. This supports the process of timely referral to Specialist Palliative Care Services.
- 1.10 The HSCP Telecare and Telehealth Hub are improving timely access to services supporting autonomy and patient self-management. A recent audit of Nurse Led Respiratory / COPD telehealth in Nov 2014 was able to demonstrate significant reductions in bed days combined with an increased quality of life for the 20 or so patients who participated. This is supported by HSCP Staff, Community Health Staff and Acute Respiratory Colleagues from Inverclyde Royal Hospital (IRH); see attached audit report (**Appendix 1**).
- 1.11 Ardgowan Hospice have a service for people with end stage COPD who would benefit from a more intensive support approach. The hospice breathlessness team are exploring the possibility of increased reach and impact by sharing methods and skills with other specialist colleagues.

IRH Hospital Specialist Palliative Care Team (HSPCT) receive referrals from up to 14 clinical wards in addition to this also Oncology OPD, A&E and the Renal Dialysis unit. Patients are reviewed generally within one working day, more often the same day of referral and working in collaboration with multi-agency, health and social care professionals a timely, effective patient centred service is achieved. It benefits from two medical sessions (0.2wte) per week supported from Ardgowan Hospice. The HSPCT have been actively involved with the Marie Curie 'caring together' heart failure project and shaping the renal conservative management clinic with particular success in Advanced Care Planning. The aim is working towards the provision of an equitable palliative care service to all patients with a life limiting disease. The team has also had input into the patient centred health and care project (relational care giving) which is now established on many wards throughout the hospital. This is helping to improve patient and carer experience through real time feedback and meaningful significant conversations.

- 1.12 NHSGG&C, like other health boards, has a network of community pharmacists who provide enhanced services for Palliative Care patients based on a Service Level Agreement. Each network pharmacy keeps an agreed stocklist of palliative care medicines and receives additional training (induction and annual).
- 1.13 Inverclyde HSCP has benefited from having access to Macmillan Pharmacy Facilitators both as part of the initial demonstrator project (2009-2013) and the roll-out to the whole of NHSGG&C (2013-2016). Flyer describing service is available at:

http://www.palliativecareggc.org.uk/index.php?action=cms.comm_pharm.

The facilitators work closely with community pharmacists, district nurses and GPs.

- 1.14 Local Care Home managers are participating in 'My Home Life' programme with Inverclyde HSCP Support and Collaboration. Sessions concentrate on transitions between sectors and Anticipatory Care Planning. They have led to increased collaborative working, particularly with District Nurses Care Home Liaison Nurses and representatives from Scottish Care within local Care Home establishments.
 - 1.15 As part of an overall improvement programme, Ardgowan Hospice are implementing 'What Matters to You'. This has been particularly successful in patients transferring from hospice to nursing homes and has been a focus of conversation enabling the patient to settle in.
 - 1.16 The use of the Supportive and Palliative Care Action Register (SPAR) tool assists with recognition of deterioration. It is being supported by local DN teams and there is a rolling programme of education being offered by HSCP Prevention and Support Advisors. GPs are also encouraged to be involved in SPAR tool usage by education from Inverclyde GP Facilitator during practice visits. The SPAR tool is also being disseminated to all GP surgeries as part of The Inverclyde Palliative Care Resource Pack. SPAR is also being implemented across all hospice services.
 - 1.17 Prescribing and Administration of Anticipatory Medicines (Just In Case Box) is supported both within patient's home and Care Home environment, as is the appropriate and timely use of McKinlay T34 Syringe Pumps. This is part of the process of delivering good symptom management which often requires significant input from DN Teams.
 - 1.18 The Marie Curie service can be called upon to support people within their own home for end of life care or for relatives/carers respite during the individuals` illness, however, this service is limited and not available to everyone.
- 2. How could it be ensured that access to Palliative and End of Life Care is equitable and available in all areas and for types of terminal illness?**
- 2.1 The use of improvement science to understand referral patterns and reduce inappropriate gate-keeping to ensure timely interventions for all based on need.
 - 2.2 A number of partnership working research projects are ongoing, as well as on the ground networking and multidisciplinary educational delivery taking place within Inverclyde.

- 2.3 Work ongoing to educate the local community with regards to services and promote an ethos of Palliative Care. Projects such as high school students education programmes (Together We Care) are continuing within Ardgowan Hospice.
- 2.4 Mrs Alison Bunce, Director of Care, Ardgowan Hospice is currently on secondment to develop, implement and evaluate a Public Health Initiative to establish Inverclyde as Scotland's first accredited compassionate community (Compassionate Inverclyde). A key component of Compassionate Inverclyde is the development of a diverse volunteer workforce. This will be evaluated within an academic framework with partners in the Public Health Network.
- 2.5 Ardgowan Hospice is a hub of undergraduate and postgraduate education for medical, nursing and AHP students from The University of Glasgow, The University of Strathclyde, The University of the West of Scotland and Caledonian University. Ardgowan Hospice also runs education sessions for local GPs and District Nurses. Further education students, undertaking vocational qualifications from partners in West College Scotland, also work with Ardgowan Hospice. The hospice gained official status as a University Teaching Hospice in 2014.
- 2.6 Mrs Hennan and Dr Milligan worked collaboratively on a very effective Care Home Training programme, educating and training for Local Authority and Health Care staff in partnership. It is planned to develop this further with more use of technology and innovative solutions.
- 2.7 Inverclyde Carers Centre run a number of training sessions dedicated to improving knowledge and autonomy of local patients and carers. Ardgowan Hospice and HSPC work closely in collaboration with a number of third sector organisations, including Your Voice. The aim is to improve the holistic care and address the needs of local people with life limiting conditions and their support networks. The HSCP now has a dedicated welfare rights team to address the needs of inpatients based at the IRH.
- A Hospital Chaplain, Mr Philip Craven, is also in post at Inverclyde Royal Hospital and provides ongoing spiritual care education for staff including GP colleagues. Ardgowan Hospice also have a Spiritual Care Co-ordinator who liaises with all faiths across Inverclyde as well as support staff, patients and families at the hospice.
- 2.8 Specialist Palliative Care Services are reaching out to Hospital and Community based services including IRH Respiratory MDT meetings, Oncology Clinic, Renal Conservative Management Clinic, Heart Failure Clinic, Respiratory Clinic and GP Palliative Care meetings.
- 2.9 Ardgowan Hospice has been supporting Cowal Hospice to develop local services, for example the establishment of Cowal Hospice and Therapy Services (CHATS) which has been successful due to a specialist secondment from Ardgowan Hospice.

2.10 Community pharmacists are not routinely informed about patients added to GP Supportive Care Register. This limits their ability to intervene appropriately and provide support and advice. Lack of access to patient records for community pharmacists in Scotland is likewise a constraint (both to access information and to document interventions). The GP facilitator will continue to highlight appropriate information sharing with Community Pharmacists with local GPs on practice visits.

3. Can you identify any areas in terms of access to Palliative and End of Life Care that should be focused on as priorities?

3.1 Utilisation of innovation and technology to have a greater reach and impact on health and wellbeing such as the use of 'Skype' or 'Facetime' to support people in their own homes. The hospice are also working with Scottish Health Innovations utilisation of innovative devices to deliver PRN medications for timely management of breakthrough pain.

3.2 Funding to develop further educational programmes and protected learning time and backfill for generalist staff and undergraduates in health and social care. This will allow them to continue to provide good quality Palliative Care and embed within practice at an early career stage.

3.3 Funding for ongoing research and innovative solutions to further develop local services and address evolving needs of the community. This includes the changing demographic data issues such as a rapidly rising number of single older adult households evident within Inverclyde. An identified potential health issue is the predicted rise in the number of people with end stage alcoholic liver disease; see Appendix 3 – report by Dr Jacquelyn Chaplin.

3.4 Equitable access to good quality Palliative Care during the 'out of hours' period. Locally Adult Community Nursing Service is working towards closing any gaps in service delivery (aiming to provide support 24/7). 'Earlybird' Service is in operation 6:00am until 8:30am, 7 days per week and is able to provide a response to requests for breakthrough medication etc. HSCP Homecare have expanded their through the night support service and work closely with District Nursing.

3.5 Develop a more cohesive and flexible workforce with a model that includes health and social care assistant practitioners as identified in the Greater Manchester Model Pilot Site to promote joined up working with less hands off for patients and clients.

3.6 Improve access to psychological services and care for marginalised groups such as people experiencing homelessness.

3.7 Ardgowan Hospice is committed to reach out to people affected by dementia and will use a complementary and collaborative approach with our partners in Inverclyde to the development of services and skills in response to the needs of people affected by a diagnosis of dementia.

Ardgowan Hospice's vision is to include an evidence based approach to care for people with dementia which will take into account not only the care provided, but the care environment and will be investing in the development and support of the staff and volunteers and to identify a Dementia champion.

- 3.8 Further development of signposting and information websites to allow wider access for patients, carers and professionals including Ardgowan Hospice, Inverclyde HSCP and IRH websites. This will enable patients and carers to become more involved in their own self-management.
- 3.9 Evolve service provision by listening to constructive feedback from patients, carers and professionals. Locally all DN Teams, as part of the national Releasing Time to Care programme, have feedback via annual patient satisfaction questionnaires relating to service delivery and interventions. This is indeed also the case for Ardgowan Hospice and community medical staff.
- 3.10 Concentrate on demonstrating outcomes through a metrics approach. Ardgowan Hospice are working with Cicely Saunders Institute to implement palliative care outcome scores to demonstrate the positive difference hospice care makes.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

- 4.1 A shift in societal norms is required so that dying is perceived as normal and then equally leading to open discussion within communities. This will facilitate discussions on issues such as ACP / Power Of Attorney and ceilings of care. Compassionate Inverclyde led by Ardgowan Hospice will support communities to have more open discussion.
- 4.2 Once the patient is diagnosed with life limiting illness, they should have the opportunity to start discussions whenever is appropriate for them as an individual, covering issues specific to their needs.
- 4.3 Cues should be addressed by all health and social care professionals involved in their care and education should be provided for all staff to confidently deal with these conversations so the 'moment is not lost'.
- 4.4 Research has shown improved quality of life scores, reduction in depression, improvement in nutrition, living longer, meeting personal goals and fewer hospital admissions when Specialist Palliative Care Teams are involved in the care and management of patients diagnosed with life limiting illness.

5. What works well in discussing Palliative and End of Life Care and how is good practice communicated? Where do the challenges remain?

- 5.1 In our experience, patients and where appropriate carers, family and guardians, when given the opportunity and time to access the level of information and resources, are able to formulate informed decisions. This may require several consultations or points of contact and this should be respected.
- 5.2 Good practice is communicated and disseminated within several forums and is embedded within the Inverclyde partnership working framework. For example GP Palliative Care Meetings, GP Forums, District Nurse Forums, Inverclyde Palliative Care JPIG, Hospice and Hospital MDTs, Clinical Reflective Practice sessions, Palliative educational sessions run by hospital, hospice and HSCP teams and through informal team discussions. The concept of reflective practice is very much an ethos of Inverclyde staff.
- 5.3 The challenges that remain are time and financial constraints, alongside more effective means of information sharing which is currently being explored across NHSGG&C.
- 5.4 To ensure that all staff have appropriate communication skills training and the infrastructure supports real time updates within – IT systems, paper trails and verbal communication.
- 5.5 In some parts of the UK the local hospice co-ordinates palliative care which is reported to work well and improve the number of people who die in their place of choice.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

- 6.1 Anticipatory Care Plans (ACPs) form an important part of the patient's experience and journey. They need to be timely, holistic, allow the patient to remain autonomous and address goal setting and ceilings of care. This needs to be a meaningful exercise. These concepts should be embedded within good clinical practice and professionals allowed the time to be able to complete plans in a significant way and share this information as appropriate.
- 6.2 'My Thinking Ahead and Making Plans' document has been disseminated to all local GPs in Inverclyde Palliative Care Resource Packs. This has been backed up by practice visits and education sessions to embed ACPs within good practice. Joint practice visits from Ardgowan Hospice and HSCP teams will further address ACPs and reinforce this as part of good clinical holistic care. The key is education and reinforcement of how an appropriately timed and communicated ACP can positively impact on a patient, their carer and family's journey.

This requires ongoing audit, improvement science and clinical reflection.

Advanced care planning is embedded in the renal conservative management clinic, this encourages and supports patients, carers and families to discuss thinking ahead and making timely decisions that are important to them. Staff members having time within each shift to enable them to have these discussions is paramount.

- 6.3 There have been a number of developments with regard to accessibility of EKIS. The improvements within the Community Nursing Information System have also assisted in embedding Anticipatory Care Planning (ACP) in day-to-day practice. A patient held 'message in a bottle' signposts visiting professionals to the practitioners involved in their care and also directs them to the location of the ACP.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

- 7.1 This should be at a level and quantity of information appropriate to that patient and should be very much individualised. Within Inverclyde a number of resources are available, for example:

7.1.1 Face to face contact with various professionals, often on a number of occasions.

7.1.2 Circulate further leaflets and contact cards such as those produced by Ardgowan Hospice and IRH Palliative Care Team.

7.1.3 Your Voice and The Inverclyde Carers Centre provide signposting to centres and provide education sessions for patients and carers.

7.1.4 Ardgowan Hospice is developing its website to be more interactive with more downloadable information.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there areas for improvement?

- 8.1 Ardgowan Hospice and IRH Specialist Palliative Care are involved with undergraduate nursing and medical training with student placements from UWS and the University of Glasgow. The medical staff are also involved in teaching communication skills to undergraduate medical students within The University of Glasgow on a plenary and tutorial group basis. Students from West College Scotland work with patients at Ardgowan Hospice and develop life skills and citizenship.

Social care students and AHPs also request placements at the hospice during undergraduate training from Glasgow Caledonian and Strathclyde Universities.

- 8.2 Education sessions based on communication are run by Ardgowan Hospice for health and social care staff. GP evening education sessions run jointly by IRH, Ardgowan Hospice and HSPC include complex case discussions and management of difficult consultations.
- 8.3 Funding for further advanced communication skills training would be beneficial. HSPC are working with IRH staff to embed reflective practice and spiritual care within Acute and Community teams.
- 8.4 Ardgowan Hospice provides communication skills training for volunteers within specific roles for example reception and retail staff as people very often tell their story to all staff groups.
- 8.5 NHS GG&C palliative care practice development team co-ordinate and facilitate a number of free (to NHS employees) palliative care modules and training days throughout the year.
- 9. How do Health and Care organisations ensure that the discussions about Palliative and End of Life Care are taking place at the right time?**
- 9.1 An ongoing programme of audit should take place to ensure quality standards are being met.
- 9.2 Feedback, reflective practice, dissemination of good practice and Significant Event Analysis are key factors. This should be embedded within an ethos of quality Palliative Care throughout Inverclyde. We are embedding 'what matters to you' within practice.
- 10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?**
- 10.1 ACPs can change throughout the patient's journey and this should be communicated verbally and electronically with staff involved in the patient's care. There should be a mechanism for regular review and information sharing by the patient's key health / social care professional / advocate; family should be involved where appropriate.
- 10.2 IT integration is a key factor as are formal MDTs and informal partnership working. Currently the Key Information Summary (KIS) is the preferred method of storing and sharing pertinent information.
- 10.3 Patient held records are another area for further exploration and consideration. These would be key for recording 'real time' priorities for Palliative and End of Life care.
- 10.4 In terms of priorities for teams, having closely working enthusiastic and dynamic professionals, whom all feed into the Inverclyde JIP and MCN are key. This drives change and evolution of the service locally and stimulates discussion at national level. This should include an active

professional group using improvement science, research and leading developments.

Mrs Christine Hennan, Mrs Thelma Bench, Dr Sandra McConnell and Mrs Alison Bunce represent Inverclyde on the Greater Glasgow and Clyde MCN. Mrs Christine Hennan is on the MCN sub-group for Recognition and End of Life Care

- 10.5 The Inverclyde Palliative Care Planning and Implementation Group have an action plan, devised and agreed by all local providers, reviewed quarterly and redrafted every two to three years. This Group is a key component in partnership working within Inverclyde; a platform for information sharing and is the future commissioning route as service commissioning changes.

Inverclyde in Partnership for Palliative Care

Telehealth Doc@Home Audit

Inverclyde CHCP has 19 patients using Telehealth (Doc@Home) to monitor their Chronic Obstructive Pulmonary Disease at Home.

Admissions and Bed days at IRH were Audited for these patients 9 months prior to using Doc@Home and for 9 months while using Doc@Home

Before these patients were being monitored with Doc@Home there was 48 Admissions and 436 Bed Days at IRH for exacerbation of COPD

While these patients were monitored with Doc@Home there was 12 Admissions and 159 Bed Days at IRH for exacerbation of COPD

Overall

75% (36) Reduction in Admissions to IRH

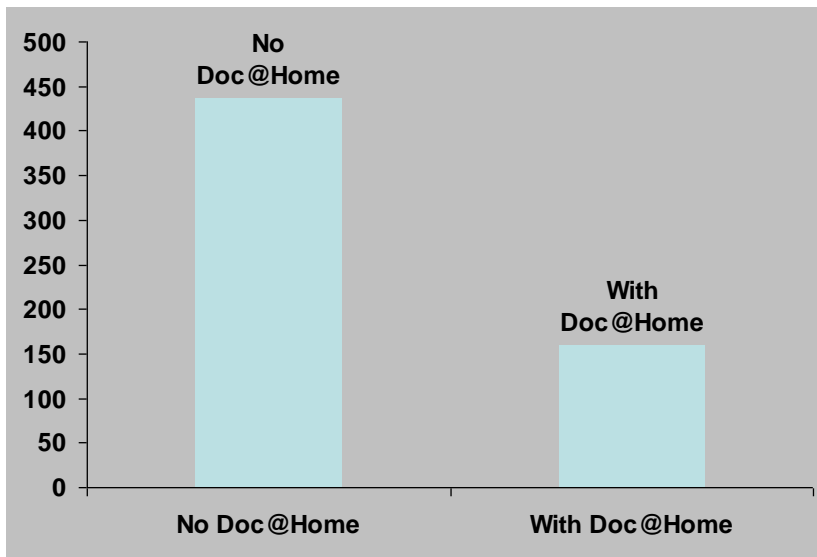
AND

64% (277) Reduction in the No of Bed days required.

In 46 occasions over the 9 months patients commenced on their Just In Case medication (Antibiotics and Steroids) which prevented further A&E attendances / Hospital admissions

Telehealth Doc@Home Audit

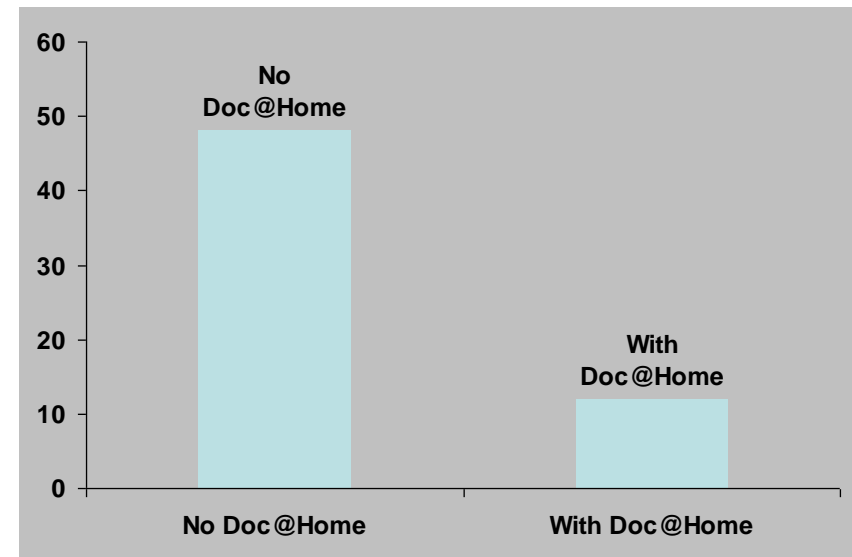
Bed Days At IRH



436 Bed Days **BEFORE** Doc@Home

159 Bed Days **WITH** Doc@Home

Admissions to IRH



48 Admissions to IRH **BEFORE** Doc@Home

12 Admissions to IRH **WITH** Doc@Home

Oct-14

JUST IN CASE
MEDICATION

WHILE USING SYSTEM AT HOME

1 YEAR PRIOR TO USING SYSTEM

PATIENTS NAME

USED

ADMISSIONS

BED DAYS

ADMISSIONS

BED DAYS

2311343068

1

0

0

0

0

1007563001

1

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16

2805363051

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2306473056

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19034730963

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43

12

44

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2102443086

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1901353028

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2

18

2004443049

1

0

0

2

8

TOTAL

46

12

159

48

436