This report summarises the outcomes of a NEMICS workshop held with key stakeholders to progress the development of a common patient held information resource across all NEMICS services.

1. Background

In 2012 the NEMICS Consumer Reference Group (CRG) identified the need and priority to develop a specific patient information resource that will assist patients and their families as they go through their cancer journey. This was further supported as a priority at the NEMICS planning workshop in February 2013.

The NEMICS Directorate were also aware that a number of NEMICS services had undertaken significant work to develop a local 'consumer health information diary or passport' to assist patients, families and health care professionals at key points in the pathway.

In responding to this CRG identified priority, NEMICS Directorate brought together consumers and key clinical stakeholders from across NEMICS services (see Attachment 1), to discuss the viability of developing a common patient held information resource that could be used across services and sectors.

The **specific objectives** of the workshop were to:

- review the drivers that influenced or are influencing consumer information initiatives
- share different ideas and initiatives for enhancing patient information
- determine the potential for NEMICS working with consumers and service providers across NEMICS health services to develop a common patient held information resource.

Key **workshop activities** included:

- presentation of the drivers for change and current service initiatives
- discussion on the benefits and barriers (along with solutions) of developing a NEMICS-wide consumer information resource
- development of a draft vision and principles for a future project
- identification of key stakeholders and communication processes to facilitate the project's development.

2. The drivers for change

Both the consumers and the health care professionals currently involved in developing local consumer resources identified common needs and issues for patients, families and health professionals as the influencing drivers for change that could be addressed through consumer information initiatives. Identified needs for consumers (patients and carers) included:

- to be more informed and in control of their health care
- to have access to information specific to their particular disease and treatment schedule to:
  - better understand their own treatment pathway and reduce their stress
  - keep track of their treatment and required appointments

- o   be able to pass on accurate information to health professionals within and external to their treating service / service providers (and so reduce the burden of having to answer the same questions repeatedly)
- o   have a record of treatment to enable issues that may arise in the future for cancer survivors or their family members, to be better addressed
- to be more aware of information resources and services that are available so that consumers are better able to initiate contact with other services as needed
- to have a streamlined package of information that is easy to access when needed.

Other key points raised by some participants included:

- the increasing evidence that consumers who are well informed and engaged with their health care cope better, adhere better to their treatment schedule and feel more supported
- the need to ensure that there is shared responsibility by the consumer and health care professionals to maintain the resource, rather than the responsibility falling solely on the shoulders of consumers
- the need to ensure that the resource is **'live'** i.e. there is an expectation that consumers bring it to every appointment and that it is regularly updated by service providers.

3.   Current work

The NEMICS CRG had identified and reviewed a range of consumer held diaries / information resources that have been developed by other organisations, among them the Breast Cancer Network Australia, Cancer Council NSW and the Hume Regional Integrated Cancer Service. While there were strengths in each of these resources, the consumers identified limitations to each.

Within NEMICS, three resources are in varying stages of development. Each resource primarily focuses on specific parts of the patient journey, predominantly within day oncology. Two prototype resources have been developed which have included feedback from service providers and consumers; these resources are ready for initial printing and piloting.

The third resource (using a simple A4 folder with plastic pockets) developed to support patients accessing oral chemotherapy and / or concurrent chemotherapy and radiotherapy, has been implemented. Feedback from consumers has been very positive.

Key learnings for the development of consumer information resources included:

- such resource development can be very time-consuming
- busy and competing work priorities of clinicians constrains the ability to progress the initiative in a timely way
- production of the resource can be very costly in the context of tight health service budgets
- communication with and engagement of all key providers who are needed to support the resource can be challenging
- the resource must be actively used as a focus of discussions between consumers and health care professionals
- consumer and service provider impetus is needed to really progress the development and implementation of such a resource
- there are diverse views on the preferred format(s) for such a resource, including hard copy or electronic resources (e.g. using a USB or developing a phone app).

4. The way forward

There was strong agreement that the development of a NEMICS wide consumer information resource was the best way forward based on:

- the availability of resources ($$, staff and NEMICS CRG) to guide and support the project
- NEMICS executive support for this within its current work plans.

Based in participants' comments (see Attachment 2), a vision statement for the future was drafted as reflected in Box 1 (with minor modifications).

Box 1: NEMICS consumer information resource
Draft vision statement

In five years' time, there will be a **SHARED, RECOGNISED** information resource, **TAILORED** to individual needs, covering the whole cancer journey and **ACCEPTED** and **USED** across all cancer services by patients, carers and professionals alike.

4.1 The benefits of a shared approach

Participants identified a range of benefits across four identified areas for developing a NEMICS wide consumer information resource. These are detailed in Attachment 3.

In addition to identifying improved outcomes for patients and for service providers, participants identified specific benefits that would result from developing a NEMICS wide resource including:

- access to a coordinating organisation with available resources including dedicated staff time and consumer engagement mechanisms
- access to a range of experience, ideas and perspectives from multiple stakeholders
- ensures that the whole patient journey is covered across services and sectors, with an emphasis on the key transition points
- recognition of the same resource across all services in the north eastern metropolitan region of Melbourne will strengthen its implementation and enable the promotion of the resource as part of normal practice.

4.2 The challenges and solutions

Participants identified a range of barriers or challenges that need to be addressed to optimise the development of a NEMICS wide consumer information resource. These barriers were then collated into the following four broad areas (see Attachment 4):

1. Difficulty gaining stakeholder engagement
2. Different and competing organisational cultures, systems and processes
3. Limited time and resources
4. Resource is too generic to meet diverse and specific consumer or service needs.

For the first three areas, group work was undertaken to review the barriers and identify potential solutions. These are listed in Table 1.

The fourth barrier identified that in order to meet diverse needs, a NEMICS wide resource may in fact become too generic and could end up meeting the `lowest common denominator´. This was recognised as a real risk. It was proposed and agreed that as part of the initial project planning, a specific risk management strategy be developed to address this.

Table 1:   Solutions to identified barriers

Barrier / challenge	Any specific issues	Solutions to address barrier

Stakeholder engagement with:
 	
Health care professionals
 	
Consumers
	• Resistance to change
	• Want to maintain the traditional ways of doing things
	• Perception that the resource would increase HCP workload
	• Changing medical model of care to one of partnering with consumers
	• HCPs see that they have ownership of patient information
	• Negotiating around differing opinions.
	
	• Consumers don't want to engage – see it as doctors' responsibility; do not want role change
	• Different cultural perspectives influencing consumer interest:
	  o people from culturally and linguistically diverse backgrounds (CALD)
	  o generational differences in need e.g. older age; adolescents / young adults (AYA)
	  o ? gender and role differences
		• Canvas everyone's opinions to enhance open communication
		• Respecting all opinions
		• Promote resource based on evidence-based practice
		• Gain support of key leadership roles
		• Use `top down' and `bottom-up' approach
		• Gain an executive sponsor at all sites
		• Create alignment with the strongly patient-centred care approach with national standards re: consumer participation.
		
		• Building strong relationships and rapport between HCP and patients
		• Have formal and informal structures in place for meetings and consumer consultation
		• Consult with consumer groups such as Cancer Voices, AYA and CALD communities.

Gaining collaboration across different organisational cultures and health service needs	• Need to remember public and private services and public / private interface • Need to identify key points for the introduction of the resource e.g. OPD, Day Oncology etc • Concerns re: HCP acceptance and use of resource – need to avoid duplication of effort.	• Ensure a clear and primary focus on consumer needs • Need for a strong education and promotional program – needs to be a universal system • Highlight benefits to health services • Use volunteers to utilise and promote the resource • Develop a community of practice to provide a shared space / forum for ideas and strategies.

Time and resources needed to support project	• Liaison with multiple stakeholders is very time consuming
	• Need to draw together individual health service issues.
		• Need for external coordinator to bring interested parties together - guidelines to progress to a common goal
		• NEMICS to bring together individual health service issues
		• Consumers to bring together different issues from different consumers (reaching the *voiceless*)
		• Working groups in each site to:
		  o bring together individual disciplines to understand the common denominator
		  o communicate with other internal providers
		• Implementation phase needs expert guidance on `how to' and to ensure sustainability.

4.3 Principles to guide the development of the consumer resource

Based on the discussions the following list of principles has been drafted to develop a NEMICS wide consumer information resource.

The resource must be developed in a way that:

- ensures that **patient-and family-centred care** remains the priority focus
- covers the **whole cancer journey** from diagnosis to survivorship or palliation
- maximises **stakeholder communication and engagement** (consumers and service providers)
- is relevant **across all services** and sectors including public, private and primary care services
- ensures **the needs of all services** (smaller and larger) are given equal consideration
- is **informed by the evidence** from the literature
- **builds on the experiences and work** undertaken by internal service groups and by other external services or consumer organisations
- is **flexible and adaptable** to different consumer and service needs, as appropriate
- demonstrates **benefit for consumers and health care professionals**
- avoids **duplication** of effort on the part of the consumer and service providers
- **is evolutionary** to enable trialing of different segments of the resource across different services to inform further development.

Based on the discussion the following key points about the resource are emphasised:

- the resource should become a mandatory part of normal practice and provide a guide for care
- it should be recognisable by all key stakeholders
- updating and maintaining the resource is a joint responsibility of consumers and health care professionals
- the final product should be available in flexible formats (eg electronic or hard copy) to respond to different consumer needs.

4.4 Stakeholder engagement and communication

It was agreed that stakeholder engagement was essential and that there needed to be multiple mechanisms to achieve this, with suggestions including:

- an executive sponsor identified at each service site
- developing formal and informal ways of gaining diverse consumer input
- working groups be established at each site that link in with across-site advisory mechanisms
- innovative communication mechanisms be developed including email and the community of practice concept.

4.5 Next steps

To progress this work as a major NEMICS initiative, Kathy Simons (NEMICS Manager) indicated the following:

- the development of such a consumer resource has been endorsed by the NEMICS Executive of which all major health service CEOs are a member
- further communication will be held with the NEMICS Executive immediately following the workshop to gain approval for work to commence
- staffing resources are currently available within NEMICS to start the developmental work within the next two months
- NEMICS will communicate with workshop participants and with other key stakeholders on the next steps as soon as possible.

Attachment 1:   Participant listing

NAME	ORGANISATION
Nadia AYRES	NEMICS – Austin Health
Hugh BURCH	NEMICS – Northern Health
Celia CHAPPELL	Radiation Oncology Victoria (ROV)
Cathie CORRICK	Mercy Hospital for Women
Jan CULHANE	Eastern Health – Box Hill Hospital
Kirsten dE HENNIN	Eastern Health – Box Hill Hospital
Melissa GWYNNE	Northern Health – The Northern Hospital
Tina GRIFFITHS	Austin Health
Nicole HALL	Ringwood Private Hospital
Dr Prahlad HO	Austin & Northern Hospitals
Lauren HODGENS	Eastern Health – Box Hill Hospital
Anne KAY	NEMICS – Consumer Reference Group
Gen LISHENKO	Mercy Hospital for Women
Anna MASCITTI	NEMICS – Service Improvement Facilitator
Jeanne POTTS	Austin Health
Janine ROSSELLY	NEMICS – Consumer Reference Group
Melissa SHAND	NEMICS – Service Improvement Facilitator
Kathy SIMONS	NEMICS – Manager
Luellen THEK	NEMICS – Eastern Health

Attachment 2: Participants' brainstorm on the vision for a NEMICS wide consumer information resource

The following lists the key points identified in a brainstorming activity to gain participants' views on a vision for a NEMICS wide consumer information resource.

In five years' time, consumers …………..:

- Will be less confused about treatment and more informed about everything
- Have specific information about their health care professionals
- Will have a resource that is in a structured format that is recognised by health care professionals across NEMICS services (like the green 'baby book')
- Will feel empowered about their illness, treatment and care
- Will have joint responsibility in their care with health care professionals
- Will have access to a resource that is updateable, 'live' and that health care professionals look at and update routinely
- Will have access to a resource that is flexible and adaptable to their specific needs
- Will have a resource that:
  o includes documentation of their experiences during treatment that will inform future care
  o acts as a prompt for consumers and health care professionals
  o is provided and used consistently across the pathway
  o covers and can be used across the whole journey including emergency presentations, survivorship and palliation.

Attachment 3: Identified benefits of developing a NEMICS wide consumer information resource

The following table lists the benefits identified by workshop participants by category. Most comments are listed verbatim with some minor modifications to enhance comprehension.

Category	Benefits
Value of developing a NEMICS wide resource	• One coordinating organisation with available resources. • *Many hands make light work* – we all benefit from cohesive effort. • Will be major network achievement and use of resource becomes part of normal practice (like supportive care screening). • Working regionally means public and private patients will be well covered across the pathway. • Ensures entire patient journey is covered particularly journey transitions – information is particularly important for these transitions. • Sharing of ideas, perspectives and resources. • Draws on a range of experiences across different settings. • Universal diary understood by everyone. • Will help to promote the concepts across health services. • Ensures agreement of terms and definitions. • Enables networking across NEMICS services.
Value of the resource for consumers	• Fully informed patients who have a sense of control over their health decisions. • Ensures key information needs of patients / carers are universally addressed. • Reduction in patient anxiety. • Ensures essential contact details are accessible. • Assists patients to traverse different hospitals.
Value of resource for service providers	• Increased communication between service providers that have previously worked in isolation. • Assists clinicians that work across health services and have to deal with one rather than multiple resources. • The transfer of accurate information leads to a reduction in patient risk (because of misinformation).
Joint consumer / service provider benefits	• Seamless patient care. • Recognisable resource across all services. • Improved outcomes for patients and health professionals. • Improved professional communication leading to better patient outcomes. • Joint responsibility of health professionals and patients to improve outcomes for patient.
General comments	• Ensure clearly defined goals and the purpose of meetings (to develop resource).

Attachment 4: Identified barriers of developing a NEMICS wide consumer information resource.

The following table lists the range of barriers or challenges identified by workshop participants by category. Most comments are listed verbatim with some minor modifications to enhance comprehension.

Category	Barriers
Stakeholder engagement – health care professionals and consumers	- Gaining agreement on ultimate use of diary. - Lack of engagement of key cancer clinicians. - Need to ensure engagement of all clinicians along the pathway to ensure all relevant information is included in resource. - Insufficient consultation with all relevant areas.
Collaboration across different organisations and cultures	- Gaining acceptance for change. - Competing perspectives and the need to meet all needs of different health services with many diverse opinions. - Care and services provided differently across different providers - Implementing change that everyone can agree on. - Different frameworks of care, different service sizes, departments and number of stakeholders. - Hospital bureaucracy. - Local needs take priority.
Time and resources	- Time constraints. - Time for stakeholders to meet as a group. - Clinicians are all busy and often do not have time to share information. - Time to get together to work together across different sites.
Scope of resource to meet all needs	- Gaining a clear understanding of what consumers and HCP see as relevant material. - Lack of agreement on the core purpose of the resource. - Conflict of ideas of what an ideal resource might be. - Gaining agreement on the extent and level of detail in the resource. - Making the tool too generic ie does not contain enough detail tailored to the individual consumer or service site(s).
Implementation barriers	- Ensuring dissemination across all sectors – public, private and primary care. - Lack of involvement of patient in their care because of: - denial - fear - not wanting to think about their illness - forgetting to take their book with them.