Supporting the patient journey – maximising patient engagement to improve outcomes

The aim of medical care is to improve survival and quality of life for patients. Those with long-term and life-limiting conditions have particular needs due to the progressive and/or long-term nature of the underlying pathophysiology. However, it is now clear that patients who are engaged in their own health and treatment may have better outcomes. Biopharma companies that take a proactive approach to patient centric care are more likely to see outcomes similar to those anticipated from clinical trial data. This can be facilitated and supported through patient support programs (PSPs) that are not only tailored to the disease type and stage, but also to the patient’s preferences and situation, adapting over time according to need. Effective support programs which combine human interaction with technology to empower and educate patients may have both short- and long-term impact on patient outcomes and healthcare utilisation.

The role of patient support
Patients with long-term conditions can benefit from support throughout their journey, from point of diagnosis through the natural history of the disorder and its treatment. This can range from education and help in understanding a new and potentially life-changing diagnosis, through to learning treatment techniques and monitoring outcomes. But putting the right support in the right place at the right time to meet the patient’s specific needs is the key challenge to the healthcare ecosystem.

The design of a PSP and its communication channels will vary across conditions. For example, a program for a familial disorder may need to be positioned towards children and their carers but then adapt over time as the child moves into adulthood. In contrast PSPs supporting patients with multiple sclerosis or rheumatoid arthritis should focus on the needs of adults who may be working and raising families. There again, PSPs for oncology may focus on complex chemotherapy needs and disease progression but then also adapt to meet the needs of survivorship.

Patients live in the ‘here and now’ and their needs change as the disease journey progresses. A well-designed PSP will need to be adapted for stages throughout the entire patient journey and cannot be a “one-size fits all” approach. As an example one patient may have been newly diagnosed with advanced disease, while another with the same condition might have been diagnosed at a very early stage and remained without progression because of good management.

Programs should also be tailored to the complexity of the disease and treatment protocols as well as any requirements e.g. REMs (Risk Evaluation Mitigation Strategies) or RMPs (Risk Management Plans) to provide longer-term data about safety or value of a drug to decision-makers. It must also take account of important cultural differences across countries and must be compliant with local rules and regulations regarding patient contact and information governance.

Key drivers for patient support
Biopharma allocate between 10-20% of the brand manager’s budget for each drug to patient support and engagement after drug launch (2), and this is expected to grow in the current value and outcomes led patient access era.

The increasing interest in PSPs is being driven by four major factors:

- Changes in long-term condition prevalence
  The prevalence of long-term conditions is growing as people are living longer, lifestyles are changing and medical care is improving outcomes.
Patients with long-term conditions such as diabetes or cardiovascular disease have to contend with an array of decisions and behavioural modifications and drug regimens. Patient education, which focusses on developing skills and increasing confidence in self-management can result in patients feeling that they are more in control and able to take steps to manage their disease (2). By providing tailored patient support biopharma can provide much needed support including increased patient activation to engage with disease management.

- Shifts in company pipelines
  Several changes in research and development pipelines are relevant including:
  - personalised medicine – biomarker or genotype driven therapies which require patient identification and education;
  - rare disease – an increasing number of therapies for rare diseases e.g. enzyme replacement or therapies for familial disorders;
  - complex “disruptive” treatment regimes – new oncology therapies e.g. immunooncology provide potential benefit but require intense treatment regimes and risk of severe adverse events.

Patient adherence to new therapies remains a constant challenge for both oral and systemic treatments and requires additional focus from launch, since expected benefits may not be realised, but treatment costs are still incurred. Measurement of real-world data, increasingly a post-approval commitment for Biopharma, will then show results may not reflect a drug’s real value and have a negative impact on perception by a variety of stakeholders, including professionals and payers. PSPs can have a positive impact on patient adherence as well as offering another means to show value.

- An evolving regulatory environment
  Biopharma and regulatory authorities are increasingly moving towards using real-world evidence to support drug development, approval and continued reimbursement. Real-world studies linked with PSPs can help companies to understand the use of drugs in ‘normal life’, research new indications, provide context for marketing or gain earlier approval. The regulatory authorities are also looking towards the collection of real-world data to support reimbursement or approval from health technology assessment (HTA) bodies. PSPs must operate within this environment and biopharma needs to be aware of what is and what is not allowed in specific countries and which regulatory requirements should be followed. It is vital to remember that a PSP should complement and never replace ongoing clinical care – the overall responsibility for patient management lies with the patient’s healthcare professional in primary or secondary care.

- Current policymaker agenda
  Patient empowerment and autonomy are key healthcare policy drivers globally and supporting patient centric care is supported at a policy level. However funding pressures are being driven by factors such as ageing and the increase in long-terms conditions and associated therapy costs. Furthermore, while innovative therapeutics such as biologics and complex delivery systems are generally more effective, they are also higher cost. PSPs can support adherence to new therapies, thus helping to ensure benefits are realised with a potential for reduced healthcare utilisation, for example in patient days and additional procedures.

Patient activation – a key foundation for patient support programs
  There is evidence that patients who are actively involved in their own healthcare, including decision-making processes, have better adherence and clinical outcomes, as well as greater patient confidence and satisfaction. Increasing these factors could potentially reduce healthcare and societal costs (4).
  Long-term condition management can be challenging, requiring lifestyle or behavioural changes and the need to handle complex regimens and monitor the disease. This requires higher levels of patient involvement - activation which can be encouraged and maintained through PSPs. Patient Activation Measure (PAM), a patient-reported score, can be used to measure a patient’s activation or involvement in managing his or her condition. These scores can be used to predict health behaviour and clinical outcomes, healthcare use and costs, patient experience rating, adoption of healthy behaviour, rates of hospitalization and service satisfaction ratings. PAM is scored from 0-100 (2,5) and works across a range of different languages, cultures, demographic groups and conditions.
  Individuals have different activation levels (Table 1) and those with high activation levels are more likely to have better health outcomes (2). The levels vary within conditions and even within socio-economic groups and interventions must be tailored to these specific groups in order to support those with high activation levels while empowering those with lower levels. PAM is therefore a foundational element of a PSP to segment patients and drive interventions or communication depending on the level of activation. Patient activation levels can be used to track changes in the quality of life, understanding of their disease or condition and levels of self-management in both individuals and groups of patients, and to assess how well interventions within a PSP are working (2).
Multichannel personalised patient engagement
Successful PSPs support the efforts of healthcare professionals (HCPs) using a tailored approach with effective use of technology, digital and traditional resources. But, technology alone cannot entirely replace people, and effective PSPs should combine human interaction with technology (i.e. multi-channel personalised engagement), providing the convenience and advantages of technology with the surveillance and supervision of HCPs. While integrating other forms of engagement into the program (digital support, videos, print material) can enhance and extend support between HCP contact and one-to-one conversations, successful programs still demand an element of face-to-face interactions for optimal results.

A recent survey in the New England Journal of Medicine, performed between February and March 2016, gained insights from 340 respondents including clinicians, clinician leaders, and hospital executives. Overall 59 percent of respondents said that increasing face-to-face time with patients was the best patient engagement strategy, followed by shared decision-making initiatives, which were highlighted by 54 percent of respondents (3).

The research concluded that currently the use of technology in patient care still requires a central human interface, acting as an ambassador for the patient and bringing consistency through the patient journey. Personalised electronic communications extend and amplify a nurse-led patient program by providing additional support through the right mix of channels, bearing in mind the demographics of the relevant patient population and the societal norms within a specific country. Patient Support Programs offered by biopharma, while not yet routine, are being driven by factors that include changes in disease prevalence, shifts in company R&D pipelines, an evolving regulatory environment and policymaker agendas.

When successful PSPs are designed with the patient in mind, they may help to maximise patient engagement, medication adherence and ultimately help to improve healthcare outcomes. However, PSPs cannot be a “one-size fits all” solution. Biopharma must tailor PSPs to the disease, drug characteristics and patient activation levels, while also considering local culture, funding requirements and regulatory restrictions.

REFERENCES
1. Source: QuintilesIMS sponsored blinded research (2014)